The experiences of healthcare staff in using the Mental Capacity Act (2005) when working with people with a learning disability

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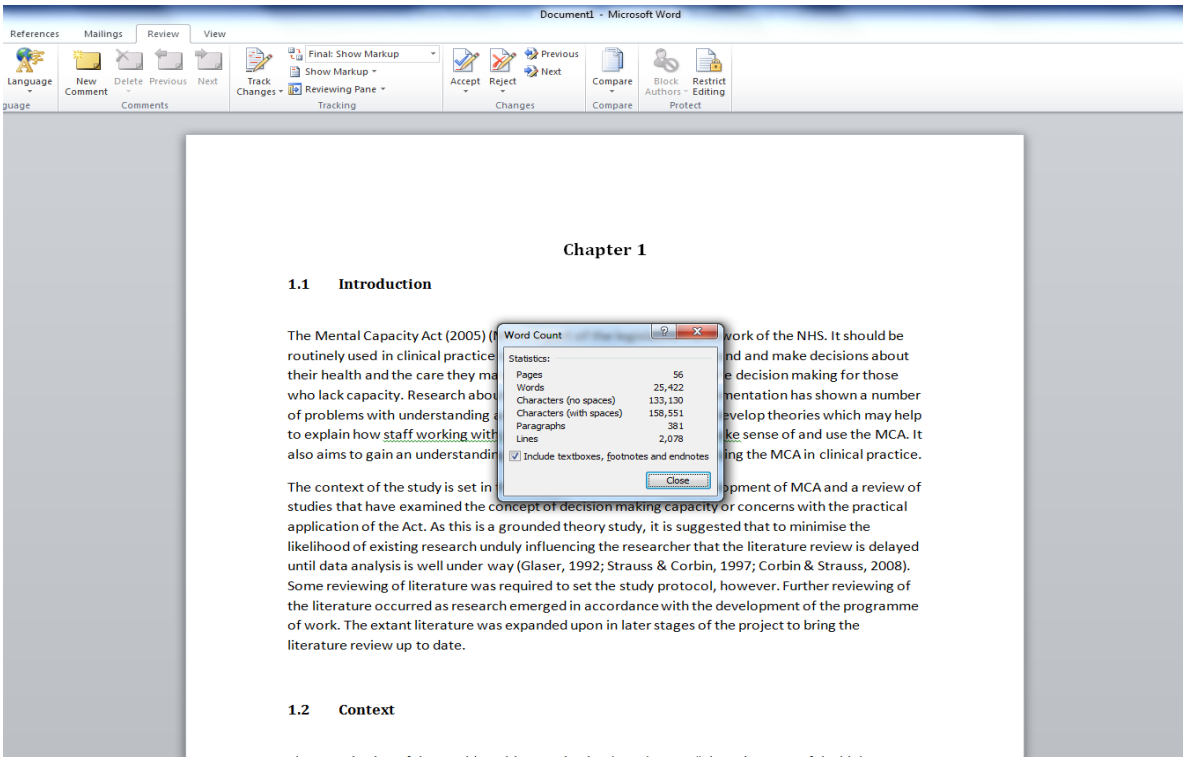
Abstract

The Mental Capacity Act (2005) (MCA) is part of the legislative framework of the NHS. Small scale studies in a range of health settings have shown that the understanding and use of the MCA (2005) varies considerably in different services and across staff of differing occupations and grades. The experiences of individual staff in using the MCA has received little attention. This grounded theory study aimed to explain how staff working with people with a learning disability (PWLD) make sense of and use the MCA, whilst also exploring the factors that influence applying the MCA in clinical practice.

This study involved 11 healthcare staff from a specialist learning disability service that had used the MCA in the six months prior to their participation in the research. Staff interviews provided narratives about how they had used the MCA. A theoretical framework was developed from the analysis which underpinned three core conceptual categories. The first core category was that of '*professional risk'* in which staff have awareness of a series of risks that pertain to themselves or the service user that could have negative professional or legal consequences. The second core category described '*emotional risk',* which affected both the staff and service user. Staff appeared to experience those risks as feelings in the form of anxiety or concern. Both *'professional risk'* and '*emotional risk'* bring about '*strategies'* which mediate the risk; allowing staff to justify and document their position, creating what feels like safe practice for both the staff and service user. Factors which facilitate the use of the Act are concerned not only with these risks but the significance of the decision that the service user has to make. The findings suggest that there is much uncertainty in the process of using the Act, some of which is due to the subjective nature of evidence gathering. The study suggests that peer support offers a range of factors important to education and development of experience in using the Act, along with helping staff cope with the outcome of decision

making. The findings have clinical implications for those involved in managing difficult assessments and decision making, including how to gain an appropriate balance between risk and human rights against a backdrop of adversity that can be present for people with a learning disability. Further implications clinically and for future research, along with limitations of the study are also discussed.



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Chapter 1

1.1 Introduction

The Mental Capacity Act (2005) (MCA) is part of the legislative framework of the NHS. It should be routinely used in clinical practice in to support individuals to understand and make decisions about their health and the care they may be offered; or to support substitute decision making for those who lack capacity. Research about the use of the MCA since its implementation has shown a number of problems with understanding and application. This study aims to develop theories which may help to explain how staff working with people with a learning disability make sense of and use the MCA. It also aims to gain an understanding of the factors that influence applying the MCA in clinical practice.

The context of the study is set in this chapter. This includes the development of MCA and a review of studies that have examined the concept of decision making capacity or concerns with the practical application of the Act. As this is a grounded theory study, it is suggested that to minimise the likelihood of existing research unduly influencing the researcher that the literature review is delayed until data analysis is well under way (Glaser, 1992; Strauss & Corbin, 1997; Corbin & Strauss, 2008). Some reviewing of literature was required to set the study protocol, however. Further reviewing of the literature occurred as research emerged in accordance with the development of the programme of work. The extant literature was expanded upon in later stages of the project to bring the literature review up to date.

1.2 Context

The Constitution of the World Health Organisation (1946) states "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition." Whilst there is no Article of the Human Rights Act (1998) to direct provision of healthcare, the Department of Health (DH), National Health Service (NHS), and The British Institute of Human rights have jointly developed a Human Rights Based Approach (HRBA) framework for national development and implementation of policies and practices in health service delivery (DH, 2008). This not only seeks to be pro-active about applying a HRBA to vulnerable groups and to challenge potentially discriminatory practices, but to empower patients in making decisions about their care. The framework sets out five core values that are implicit to Human Rights (HR); Fairness, Respect, Equality, Dignity and Autonomy (FREDA) and expects NHS trusts to embed these principles into all aspects of healthcare provision – including the welfare of its employees.

Admirable as this is, for people with learning disabilities (PWLD), human rights are 'routinely breached' (Joint Committee on Human Rights, 2008) and accessing and receiving quality care is compromised. Reports such as those by Mencap (2004, 2007) have shown how for some people with learning disabilities seeking medical attention from the NHS has led to negligence and death. The reasons for this include; the attitudes of staff towards PWLD, diagnostic overshadowing, and the standards of care offered being 'indifferent'. The discrimination displayed in the report Death by Indifference (Mencap, 2007) shows a failure to see the patient with a learning disability as a person or recognised their needs as valid, and as a result a failure to recognise individuals' human rights. This is echoed in the report Healthcare for all (DH, 2008), which claims that PWLD are invisible to services and that in general,

healthcare services have often failed to provide adequate LD awareness to staff. Furthermore, the use of the legislative framework regarding the Mental Capacity Act (2005) (MCA) and Disability Discrimination Act (2005) (DDA) is not pro-actively managed with respect to performance and compliance: they have not been incorporated fully in training programmes nor part of routine clinical practice in most services (Healthcare for All, DH 2008). This raises ethical and, possibly, legal issues relating to service provision and potentially compromises the quality of care and human rights of PWLD. Fyson and Kitson (2011) report that significant abuses of the human rights of PWLD occur both directly (to the person by an individual within a service or institution) or indirectly – through the neglect of equitable provision. Breaches of such legislature "constitute criminal offences" (p311), and a lack of regulation serves only to compound the negation of the human rights of PWLD.

1.3 The Mental Capacity Act (2005)

Prior to the MCA, substitute decision making due to lack of capacity was regularly made within health and social care services. The 1990 Community Care Act which supported people moving out of institutions and into community living brought about the opportunity for service users to be able to make more of their own decisions. The Mental Health Act (1983) provided some guidance on substitute decision making, and 'best interest' decisions were provided for via the Court of Protection (Court of Protection Rules, 2001). Later, further guidance about assessment of an individual's capacity regarding specific issues was developed by the British Medical Association (BMA) and The Law Society (2004), in which a functional assessment (rather than an outcome or status based assessment) was favoured. The difficulty remained however, that without legislature, the assessment and decision making process was too weak, and failed to adequately support the rights of vulnerable people (Nazarko,

2004). There remained a potential that assessment of capacity was not optimal and best interest decisions may not have been wholly in the best interests of the individual, thus only when decisions were challenged through the courts could the lack of safeguards be observed explicitly (Suto, Clare & Holland, 2002; Suto, Clare, Holland & Watson, 2005).

The Mental Capacity Act (2005), and later the Deprivation of Liberty Safeguards (2007) (DOLS), were introduced to balance the need to support personal choice and to protect vulnerable individuals (Jones 2010). This provided a framework for those charged with assessment and substitute decision making to work within. The Act covers day to day decisions as well as major life events such as moving home, managing finances or consenting to healthcare intervention. The MCA does not cover decisions concerning family relationships such as marriage or civil partnerships or sexual relationships. However the Act can be used to protect those vulnerable from abuse or exploitation (Department of Constitutional Affairs, 2007). The MCA (2005) sets out five statutory principles which regard an individual's capacity to understand, to weigh up the consequences, and given these circumstances, be able to make their own decision, even if unwise. The statutory principles are that:

- A person must be assumed to have capacity unless it is established that they lack capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he 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 his best interests.

- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Importantly, the MCA (2005) acknowledges that an individual's capacity can vary (due to condition and circumstance) and given this, the Act is *decision-specific*. For example, an individual may have capacity to make decisions about where to live, but not to manage aspects of their finances. In effect, the introduction of the MCA provided health and social care professionals with a safety net with which decisions can be made on a balance of probabilities and reasonable belief (as opposed to the legal brief of 'beyond reasonable doubt'). The issue of making unwise decisions can be contentious, and can engender protective feelings in carers. Essentially, decisions that are made by people that are rash or put themselves in a vulnerable position do not signal a lack of capacity; it is the ability to make a decision and not the outcome which is of consideration. Thus, the MCA can be used by anyone with concerns about a person's capacity. The application of the Act and helping people to make their own decisions, however, can be bewildering. There is an accompanying Code of Practice (Department of Constitutional Affairs, 2007) to support those thinking about using the Act which sets out the framework and provides guidance and scenario based examples. Across the NHS training in the MCA is provided in various ways, including e-learning environments, and comprehensive medico-legal training provided by solicitors contracted by Trusts. Training however is not standardised, and variation in provision may lead to parts of health and social care services not receiving adequate training (regular, mandatory) through their workplace. In effect some healthcare professionals may receive formal training but other allied health service staff may not receive any. This could lead to greater risks of poor understanding of capacity issues, weak assessment and problematic decision making. A further possible problem with this lack of co-ordinated training is that it

may set up fears and myths about what is expected or required in practice which in turn may compromise the confidence and competence of the practitioner (Willner, Bridal, Price, John & Hunt, 2012).

1.4 Potential difficulties with the MCA

Although the MCA is designed to be adaptable to every circumstance, there are some potential challenges to using it. There can be difficulties with the assessment. A person may lack capacity at one time, but soon after that capacity could change (in recovery from a minor head injury for example). It is possible for assessors to miss fluctuations, especially if separate team members make assessments at differing time points. It could also be argued that for some the assessment process may not be clear cut, indeed the term 'reasonable belief' permits subjectivity as long as decisions are justifiable (BMA, 2008). Shah and Heginbotham (2008) identified limitations in the application of the MCA with Black and Minority Ethnic (BME) groups. Language, religion, culture and gender issues may need to be addressed in order to make the assessment understandable and sustain the values of the MCA. Bilingual healthcare staff are an exception and lay interpreters (especially family members) should be discouraged due to the potentially emotive nature of the issues at hand. The role of Independent Mental Capacity Advocates (IMCAs) could help with this, but it may be a resource implication that services have to manage (Shah & Heginbotham, 2008).

1.5 Research on the use of the MCA

The MCA (2005) applies to everyone, and as it is part of the legislative framework of the NHS, it should be incorporated into routine practice in health and social care.

However, small scale studies in health settings in the UK have shown that the understanding and use of the MCA (2005) varies considerably among staff.

With emergency healthcare staff, Evans, Warner and Jackson (2007) found a third of accident and emergency (A&E) doctors gave incorrect answers to factual statements about capacity and consent. A&E nurses knew less than doctors, and ambulance staff fared the worst. Importantly, 15% of the 86 respondents (across all grades of staff), wrongly believed that people can be given medical treatment against their will. This was quite a small study, and the findings are perhaps predictable given that the remit of ambulance staff may differ to that of other health professionals - presentation with life threatening trauma requires an urgent response which may not consider capacity to consent to treatment (although this does not remove the legal responsibility to consider it) (Department of Constitutional Affairs, 2007).

Fisher-Jeffes, Barton and Finlay (2007) examined the knowledge of informed consent amongst 51 doctors (25 paediatricians, 26 other clinicians) using 10 vignettes of situations pertaining to parental responsibility and consent for medical treatment for children. Whilst paediatricians did have greater knowledge than other clinicians, there were significant gaps which may expose risks to best practice. Where there are gaps in knowledge it could be assumed that clinical practice in identifying those who may require substitute decisions is not standardised within a given service. Therefore, some service users will be receiving care which is decided upon by judgement other than issues of capacity. This way of working should be discouraged, as Worthington (2002) reports “Lingering paternalism is not part of good practice, and cannot be excused by being disguised as merely beneficent intent (or ‘doctor knows best’)”. (p.378).

In a small scale survey of LD psychiatrists, Sawhney, Mukhopadhyay and Karki (2009) found that whilst the Act was welcomed as an improvement to patient care, there were gaps in knowledge, such as when to involve an independent mental capacity advocate (IMCA). Respondents also recognised that an implication of the introduction of the MCA (2005) was an increased workload. However the MCA (2005) cannot be disregarded nor decisions be made due to time or financial pressure.

Willner, Smith, Payne-O'Donnell, Parry and Jenkins (2007) suggest that the MCA Code of Practice (Department of Constitutional Affairs, 2007) emphasises the need to seek 'expert' help, which has created pressure on psychologists and psychiatrists who could be assumed to have greater knowledge about mental capacity. Willner et al, (2007) recommend that psychologists should only become involved in assessing capacity when there is 'clinical' potential and the referral source is through the multidisciplinary team (i.e. the service user is known). They suggest that there is a concern that the use of psychology would be inappropriate in many cases and draw heavily on staff resources. Willner, Morris and Fisher (2008), provided a consultation model to care managers at a local LD service as they assessed 45 service users for capacity to manage direct payments. All but one service manager had received some training on the MCA (2005). They stated that they were low in confidence on how 'well informed' they felt about the Act and using it. This did improve after the programme of work, but it was not clear whether this was due to practice effects or the support offered by the consultation (or both). Although improvement in confidence was reported after the scheduled work, some voiced concern about decision accuracy. Importantly, all care managers wanted more training, yet despite being provided with guidance, most managers had failed to read it ahead of time. The reason for this is not speculated upon in the paper, but it could suggest that there are time pressures on staff which prevent this, or avoidance occurs perhaps

due to the lack of confidence. A further implication noted in the study was the possibility that if a service user is assessed as lacking capacity to make a decision, it might put pressure on service resources to provide extra care or support. Whilst is it not suggested that this is a factor which may influence the use of the MCA (2005), it does highlight that there are greater consequences of the assessment process.

Similar issues were raised in a recent study by Willner, Jenkins, Rees, Griffiths and John (2011). The knowledge of 40 healthcare professionals working in a LD service (excluding psychiatrists and psychologists) was examined. Whilst almost all of the participants had received training, there were considerable gaps in knowledge. The study raised issues about how staff identify capacity concerns (i.e. proactive or reactive), responsibility, reluctance in decision making, assessment and risk. Workload pressure was implicated in the staff members' lack of opportunity to take up extended training. Willner et al (2011) report that the barriers to implementing the MCA (2005) go beyond a lack of knowledge and could be due to a lack of support at a service or managerial level or whether the service user needs extra help as a result of the decision. Also, the potential weight of responsibility for the decision was suggested as a factor contributing to the general reticence to use the Act. Despite this being a real concern, decisions that are challenged by others to the point of legal action are rare in services for PWLD. This is not greatly understood, perhaps the assessment and decision making is working well, but it may be that PWLD remain rather invisible and their rights are not proactively managed despite publications such as Healthcare for All (DH, 2008) and the BBC 'Panorama' programme bringing scandals such as Winterbourne to public attention (Kenyon & Chapman, 2011). For a review of events and criminal proceedings post documentary, see (http://www.bild.org.uk/news-and-whats-on/winterbourne-view/ date retrieved 11th November, 2012).

1.6 Conducting assessments and decision making

Despite the Government's 'Mental Capacity Implementation Programme' in 2007 which supported organisation and processing of the Act into the public arena, research described in the previous section highlights a number of factors which have compromised services embracing the MCA, including training issues, resource implications, (Hardy & Joyce, 2009; Shah & Heginbotham, 2008; Willner et al 2011).

The method used to assess capacity has also been a concern. The 'status' approach e.g. consideration of mental health, brain injury or communication difficulties is problematic as these issues do not automatically mean that a person cannot make a decision, (Wong, Clare, Gunn & Holland, 1999). The introduction of the MCA favoured a 'functional approach' to the assessment to overcome limitations of the status approach (Myron, Gillespie, Swift & Williamson, 2008). Yet, rather than structure thinking around the assessment and developing confidence, Skinner, Joiner, Chesters, Bates and Scrivener (2011) suggest that healthcare professionals are reluctant to take responsibility or make decisions because of a belief that they lack appropriate training and skills, and are concerned about gathering the right evidence. Furthermore, Skinner et al (2011) note that the five principles of the MCA may create an impression that there is a 'formula' to assessment – one which healthcare professionals largely feel they do not understand. This may have created a myth that assessments of capacity should be carried out by psychologists or psychiatrists (not helped by reference in the Code of Practice (Department of Constitutional Affairs, 2007) to assessment being referred to an 'expert' as noted above).

These factors concerned Skinner et al (2011). They proposed that structured decision making would be helpful so they developed a two phased functional assessment to support eye care specialists when working with PWLD. Phase one consisted of 'screening' the individual's ability to process and recall information. Once this was established, the second phase introduced details about the intervention which were checked for understanding. The development of this process was backed by appropriate guidance and resources (e.g. Mencap guidelines) to support the information exchange between staff and service user. Breaking the assessment down and having a flow chart which sign-posted stages and actions appeared to structure the process and reduce staff anxiety in approaching assessment. The authors report that this method is transferable as a useful guide to assessment in any domain, not just healthcare. There are however some limitations to this study. It only involved nine people, of which only two had the second phase of the process (information about the intervention) provided. It would be useful to see how the process works with more people who have the second phase applied, and look at what happens if capacity is lacking, or where capacity is recorded and an unwise decision is made. There is face validity to this instrument, but it may be compromised when complex issues or grey areas arise. It also fails to account for fluctuations in capacity, particularly if the assessment process takes a number of weeks. Essentially however, it does provide a sensible structure for use by those who may feel unsure about using the MCA.

The issue of decision making within the MCA has also received academic interest. It is important to note, however, that deciding on whether the MCA is needed at all is a decision in itself. Despite the Code of Practice (Department of Constitutional Affairs, 2007) stating that even "day-to-day matters - like what to wear" (p16) can be accounted for, it is unlikely that those suspected of lacking capacity will have *every* decision ahead of them managed through the MCA. Ferguson (2010) found that

PWLD were able to make ‘everyday’ decisions but when healthcare issues came up, those decisions were often made by others. This suggests that the type of decision, or the need for an intervention, may be a trigger to applying the MCA. In an audit of documents regarding 68 Community Mental Health patients (52 older adults, 11 working age adults and five LD adults) who lacked ‘decision making capacity’, Sorinmade, Strathdee, Wilson, Kessel and Odesanya (2011) found that decisions were needed with respect to treatment, housing and finances (i.e ‘everyday’ decisions were not accounted for). Only 54% of records had information about the process and in some cases there was no information about why the MCA was implemented. Further to this, only 57% recorded best interest decisions clearly. On a positive note, the family and carers appeared to be consulted in many cases. Sorinmade et al (2011) noted that “clinicians are more likely to assume that patients have treatment consenting capacity as long as they do not object to the proposed treatment” (p.177). Hence motivations for the use of the MCA are also important to understand.

1.7 Introduction to the current study

The research about the MCA in relation to healthcare services suggests there are difficulties with its use. This may be due to a variety of factors such as variation in training and knowledge; fears and expectations surrounding the consequences of implementing the Act; and difficulties with the actual performance of assessment and decision making. However, exploration of what is happening tends to fall short of examining the real experiences of those on the front line that are expected to apply the Act. Whilst Willner et al (2008, 2011) and Sawhney et al (2009) speculate as to why the legislative framework appears not to be closely adhered to, understanding the most influential factors requires exploring the experiences of staff. Examining

staff reports about how they use the Act may uncover some of the processes involved in working with complex legislature. This way of examining the use of the Act could bring about an understanding that may support staff in their role and provide optimum opportunities to safeguard the rights of service users. It would be useful to focus on healthcare staff working in a LD service as it could be expected that they are faced with implementing the Act more regularly than healthcare staff in other services across the NHS. Examining the use of the MCA (2005) in this way has not been done previously and may be better accounted for by using qualitative methodology. The experiences of staff, their understanding of and motivations for the use of the Act could provide a valuable contribution to the knowledge base, identify clinical issues that affect implementation and care, and further develop training tailored to the needs of those that use the MCA.

1.8 Research aims

The research questions are: 'How do learning disability healthcare staff make sense of and use the MCA?' and 'What factors influence learning disability healthcare staff's use of the MCA in clinical practice?'

The Mental Capacity Act (2005) does not solely apply healthcare, but is part of the legislative framework of the NHS (Department of Health, 2009) and states that capacity must be assumed unless it is established that capacity is lacking. There are times when people accessing health (or allied social care services) may lack capacity to make some decisions about their care. The frequency of a 'lack of capacity' to make a decision is likely to be higher in learning disability services than other services across the NHS. Research described in this thesis suggests that there are difficulties with knowledge and implementation of the Act, but less is known about the

mechanism of this; what is happening for the people who need to use the MCA and how do they make sense of it? It may not be as clear cut as a lack of training or resources, and could involve complex social processes between practitioner, the service user and allied carers. The research will explore the narrative of staff experiences of using the Act. This will focus not only on their knowledge and practice, but how they experience the implementation of the Act drawing upon factors that perhaps facilitate or hinder them, and the effect this has on them in their role. The following research aims are set out to help achieve this:

- To understand the processes involved that help staff make sense of the Act.
- To explore the factors that may facilitate or inhibit the use of the MCA.
- To develop a theoretical understanding to account for the above.

Chapter 2

2.1 Method

This chapter describes the approach and methods of data collection and analysis. Grounded theory (GT) as a methodology is discussed, and then later in the chapter the common methods in GT are outlined alongside descriptions of how they were used in this study. The aims of the study, participants and relevant procedures involved are also reported here.

2.1.1 Research design

The project aims are to explore experiences of healthcare staff, generating a theoretical understanding of how they make sense of and use the MCA and of the factors which influence the application of the Act. As the study is looking at understanding social processes, qualitative methodology which is concerned with the social world and the construction of meaning that interactions, processes and events have for people in a given society is the best way to approach this (Sullivan, 2010). The philosophy of this and why it is important is explored in the next section. There are a range of qualitative methods that would support this such as Interpretative Phenomenological Analysis (IPA), discourse analysis, or grounded theory (GT). IPA looks at the meaning behind experiences from a homogeneous sample (Shaw, 2010), whereas grounded theory examines experiences, creating a theoretical model to account for what is occurring in social processes within a purposively selected population. As this research is seeking to generate a theoretical understanding of the processes involved in using the MCA, GT is most suited to this study.

2.1.2 Philosophy and Grounded Theory

In researching social experiences, different philosophical paradigms and positions come into play. These are important because they set a context for questioning the nature of reality (ontology), the origins of knowledge (epistemology), issues of demonstrating what is understood (logic) and how these factors together contribute to the understanding of the social world (teleologic) (Maykut & Morehouse, 1994). Researchers can differ in their philosophical approach which ultimately directs their research questions, theory development and testing. It is therefore crucial that the researcher is aware of their own ontological and epistemological position and states this for the reader (Mills, Bonner and Francis, 2006). The following section outlines epistemological arguments that surround GT methodology and follows with the researcher's statement of position.

Grounded theory (GT) has become an accepted qualitative research method in which to examine social phenomena (Kennedy & Lingard, 2006). The origins and development of GT are well documented and are attributed to Barney Glaser and Anselm Strauss (1967) through their influential work with terminally ill people about dying. Rather than test a predetermined hypothesis, Glaser and Strauss (1967) proposed that research questions must be explored in a way that allows the development of a theory from the context and perspective of the participants. The role of the researcher is to try to remain separate from preconceived knowledge and ideas and be led by observations made through the data. Generally speaking however, the researcher is often also part of the culture and thus some 'knowledge' is inescapable. Glaser and Strauss (1967) proposed that the coding procedures and development of concepts would eventually lead to the emergence of theories that were grounded within the data.

Whilst the parameters of GT as a research method has remained relatively stable, over the last four decades other theorists have challenged the assumptions behind this original research paradigm; even Glaser and Strauss have developed divergent views since their seminal work. It is important to take a brief look at the epistemology of various different approaches to GT to provide context for the position of the researcher of this study.

2.1.3 Post positivism

What Glaser and Strauss had individually brought to the development of this research method was born out of their differing (and in some ways competing) educational philosophies (Charmaz, 2006). Glaser was schooled in positivism which requires that research be observable, objective and structured, and importantly has good reliability and validity. Strauss' background was from sociology and symbolic interactionism (e.g. Blumer, 1954, 1969); an understanding of how all human actions, interactions and meaning are socially constructed. He believed that people are 'active agents' of such processes (even by choosing to do nothing). The combination of their approaches led Glaser and Strauss (1967) to believe their methodology to be 'inductive.' This was aided by the parallel process of data collection and analysis and holding off reviewing the literature until concepts had begun to emerge from the data. Thus the structured aspect was still important, but there was a new understanding about how *objective* the drive to develop a theory would be. This became known as *post-positivism* (Kennedy and Lingard, 2006), where the concept of 'truth' may never be completely captured, yet research into social processes would nevertheless remain rigorous. By the 1990's Glaser and Strauss had divergent views on the method of GT. Glaser (1992) accused Strauss of writing *Basics of qualitative research* (1990) as a conceptually different method than their earlier work on dying. Glaser (1992) suggests that what Strauss and Corbin (1990) proposed is that

grounded theory can be in some way prescribed; having a formulaic way of handling the data that forces it according to preconceived ideas.

2.1.4 Post modernism

Later, and in contrast to earlier post-positivism, proponents of the epistemology of *post-modernism* rejected any search for 'truth' in science, and researchers such as Clarke (2003) claimed there to be multiple perspectives that must be appreciated in social research, each constructing their own reality which is relative to that of other members of that society (Vidich & Lyman, 2000). Clarke (2003) stated that this 'postmodern turn' brings about a host of philosophical challenges that do not fit well with traditional GT methodology. Postmodernism is complex and polar to modernism with its universality, stability and rationality. The postmodern turn emphasises locality, partiality and instability in society. This then poses particular difficulties for research. Even if there are no 'truths', situations or processes under scrutiny must be examined in a trustworthy manner. Building on from Anselm Strauss' perspective on the social world, Clarke (2003) proposed that GT requires a specific technique of *situational analysis* and maps to orientate and guide researchers in identification of key data and situations and assist with more "provisional grounded *theorizing* rather than the development of substantive and formal theories as the ultimate goals." (p559).

2.1.5 Constructionism

Charmaz (1990) was a proponent of another approach to GT. Her study on chronic illness introduced her positioning as *social constructionist.* Her sociological background led her to understand that the researcher's own social constructs interplay with that of the participant and include important issues such as negotiation and power. Charmaz (1990, 2006) believed that the post positivist movement was

too reductionist, and risked losing the context of the experience. She criticised the work of Glaser and Strauss (1967) and Strauss and Corbin (1990) for not moving away from positivism or objectivism in the use of GT (Charmaz, 2003) and positioned constructionism as “a middle ground between postmodernism and positivism.” (Charmaz, 2003, p510). Drawing on symbolic interactionism, phenomenology (the study of lived experiences as a conscious process) and Marxism (with its use for relating experience to more prominent societal structures), Charmaz (1990, 2006) claimed that the crux of GT is that knowledge is not induced, inferred or otherwise ‘known’, but that knowledge is constructed. It is a co-construction between the participant and the action, or their social interactions as much as it is constructed by the researcher in their attempts to state the facts from the data as they see them.

The constructionist approach is not without criticism. Craib (1997) reported that constructionism is “anti-realist” with its insistence on claiming that nothing is objective, and that even the lived experience is not based on a perception of reality (Andrews, 2012). Corbin, (Corbin & Strauss, 2008) rejected epistemological arguments stating that the evolution of various philosophical perspectives which challenged reality and the search of truth, placed the researcher at the centre of the study, and to this end risked the purpose of the research. In a critique of constructionism, Glaser (2012) stated that often qualitative researchers are too concerned about the ‘accuracy’ of their analysis, fearing misinterpretation or developing a theory that is rejected by the participants. Like Corbin (Corbin & Strauss, 2008) he is concerned that heavy emphasis on the process may lead to a loss of sight of the aim of the research: to develop a theory – nothing concrete, just an abstraction from a particular context. For Glaser (2012) the process of *conceptualization* of hidden processes is more important than the precision of the narrative. He accuses Charmaz of misunderstanding GT, particularly in her striving for descriptive accuracy over concepts, her attempts at neutralizing bias with ‘co-

construction', and making the position of the researcher too prominent. Glaser (2012) suggests that construction is a small part of GT and accuses Charmaz of not considering conceptualization and thus not following GT, merely that of a qualitative data analysis method.

The author of this thesis also takes issue with some of the constructionist stance. Reading Charmaz (2006) one can understand the social construct aspect (i.e. how part 'A' impacts on part 'B' etc.) but what is missing are two key components. Firstly, this assumes the researcher to be unable to think critically or to be objective. Secondly, it assumes that by labelling the relationship as constructed this then somehow eliminates (or at lease reduces) bias. The researcher has biases and prejudices. Acknowledging that the researcher is different and thinks differently to the participants are biases and power issues which have to be stated. To this end Charmaz (2006) addresses power quite crudely. She appears to show how overt power differentials work yet believes the work is collaborative; a consenting participant may not be an equal collaborator. The researcher observes and makes sense of the latent processes - of what is *not* said as much as what *is* said. This is subjective reporting of an interaction, not construction of processes.

2.1.6 Epistemological statement

The researcher recognises some influence from her previous quantitative research experience (a positivist position). However, clinical psychology training has supported a movement away from this and her own ontology and epistemology is re-considered in light of her influence on the development of the programme of research, from the research questions to the protocol, interview and analysis. It is understood that the relationship not only with the participant but the structure of the study and its progression is born out of her understanding of the world. The researcher's perspective is ontologically more relativist than the realism of positivist epistemology,

and thus holds some social interactionist ideas about knowledge (Cooper, 1997). This could suggest a constructionist position, but given the critique above, it seems that there are a number of challenges to the methodology. The aim is not for the work to be collaborative; the participants should be primary, and the researcher's job is to uncover latent processes and the work to be abstraction of concepts that theorise about *a* version of truth. To this end, this researcher's position is post-positivist and much in line with Glaser and Strauss, (1969).

Further information about the researcher's experiences of working with people with a LD, healthcare professionals and the use of MCA, along with her expectations of the research can be found in the reflexive statement, section 2.5.

2.2 Procedure

2.2.1 Ethical approval

Approval for this study was granted by the University of Liverpool's Doctorate in Clinical Psychology Research Committee in January 2012. Subsequent to this, ethical approval was sought via application through the Integrated Research Application System (IRAS) and gained from the local Research and Development Committee of the NHS Trust in which this research was carried out in April 2012. Copies of both approval letters can be found in appendix A.

2.2.2 The service for people with a learning disability

Participants were recruited from a specialist NHS health service for people with a learning disability. Service users are adults with a learning disability who additionally have physical, psychological, behavioural or communication needs that require

support. There is also specialist provision within the service for those experiencing acute crises, acquired brain injury, or require forensic services. All of the participants in this study worked in community services or at the acute admissions ward (a ten bed, mixed sex unit).

2.2.3 Recruitment

The researcher met with service managers to gauge their interest in the subject and whether the project could be supported (given issues such as time and number of staff participants needed). Service managers showed a keenness to be involved, and invited the researcher to a series of team meetings across different sites to introduce the study. At each site, members of staff were given copies of the participant information sheet. A number of people registered their interest in participating in the study and provided contact details.

From May to December 2012, staff that had initially shown interest were contacted as per the needs of the study, balancing this with the needs of the service (i.e. not taking two staff away from one part of the service in a short space of time).

At each interview the participant was given a further copy of the Participant Information Sheet (B), and asked if they had any questions about the study. Consent forms (appendix C) were then signed by participant and researcher.

2.2.4 Participants

Theoretical sampling was used to aid recruitment into the study. This method maximises the potential for the processes under investigation to be explored within a given population (Glaser, 1992). In the first instance, three healthcare staff aware of the study volunteered to be approached for participation. After the third, it was considered that a participant other than a nurse may add variance to the data (testing to see if the emergent concepts would remain). At the end of the first four interviews,

the next four were purposively selected, again dependent on their role in the service, hoping to gain insights from people who worked in a specific capacity to see if variance in the conditions of working still produced similar social and psychological processes. The final participants were also selected based on the hypotheses generated from the data and what validation or refinement they might offer.

The inclusion criterion was that the participants had to have been involved in the application of the MCA within six months of being recruited to the research.

Research interviews were conducted in a private consulting room at the service and took between 25 - 50 minutes.

All participants were professional healthcare staff working at a dedicated NHS Mental Health Trust learning disability service. Of the 11 participants, nine were nurses; one person was a speech and language therapist and one, a clinical psychologist. This information is not presented in the table 1 to preserve anonymity.

Table 1: Participant demographics

Participant number and Name [1]	Length of interview (minutes and seconds)	Years (range) working with PWLD	Ethnicity
1 – Anna	45.32	5-9 years	White British
2 – Ben	38.42	5-9 years	White British
3 – Cath	51.10	25-29 years	White British
4 – Debbie	42.46	5-9 years	White British
5 – Ella	33.56	30-34 years	White British
6 – Fay	29.29	25-29 years	White British
7 – Gina	22.59	25-29 years	White British
8 – Harry	40.32	20-24 years	White British
9 – Iris	28.38	35+ years	White British
10-Joanne	24.22	1-4 years	White British
11 – Kerry	40.11	15-19 years	White

2.2.5 Distress and confidentiality

Confidentiality of participants was maintained throughout the study. The researcher did not use the name of any participant in the initial recording, and assigned each a unique number as an identifier. Confidentiality was further supported by holding recordings and transcriptions in a separate place from consent forms.

Prior to interview, participants were reminded explicitly about preserving anonymity of service users during discussion of their working practices. Also information about managing distress, breaches in confidentiality, or information that may indicate

[1] Pseudonym used for descriptive purposes

compromised practice by the participant were discussed prior to consent. Contact details for the study supervisors were available in the participant information sheet.

Concerns raised by the researcher were discussed with the research supervisors without identifying the participant. Whilst ethical issues with the potential for further action were discussed in supervision, no issues were deemed significant enough to warrant further follow up.

2.2.6 Data protection

All interviews were recorded and transcribed. Five of the interviews were transcribed by the researcher. Further interviews were transcribed by members of the secretarial team at the University of Liverpool's Institute of Psychology, Health and Society. As no participant names were used during the interview, anonymity was preserved. Post transcription, the researcher removed names of people (e.g. other staff or colleagues), places or services that could serve as identifying markers from saved copies of transcripts. In accordance with University policy, on completion of the doctoral programme, paper copies of transcripts will be destroyed. Electronic data will be held by the data custodian (project supervisor) at the University for five years.

2.3 Grounded theory

2.3.1 The method

Far from being 'free' from the constraints of traditional quantitative research, GT observes some structure in its approach to data analysis in a way that each lead in the data can be examined in order to ensure that many possibilities are represented that could account for the phenomenon. By using the constant comparative method, and collecting data about the phenomenon from many sources, abstraction of latent

concepts will develop (Glaser, 1992). This section will describe the key elements that underpin GT as a qualitative method in relation to the development of this study.

Data collection and analysis are part of a simultaneous process (Strauss, 1987; Glaser, 1992). From the first interview, the researcher codes micro-analytical accounts from the narrative, this in turn should develop the researcher's curiosity about what is being said. From data provided by a small number of purposefully selected participants, changes can be made to subsequent interview schedules to gain a deeper understanding of the issues that arise.

2.3.2 Developing a research question

Despite differing perspectives, most GT researchers agree that gaining thick and rich descriptions of processes and interactions are important to examining and understanding what is going on (Corbin & Strauss, 2008; Charmaz, 2006). The starting point is the research question itself. It should be without presupposition; without a basis which is founded upon previous research; it should not seek to test, improve or even disqualify any theory already in existence. Rather, the research question is to wonder and to be curious about *what* is happening in the social world. The research question should be one which allows the examination of social processes that occur in relation to a given experience (e.g. dying, Glaser & Strauss, 1965, or chronic illness, Charmaz, 1990). In this study, the research questions how healthcare staff working with people with a learning disability make sense of and use the MCA. Participants may have a variety of views on what facilitates and hinders them in their role, but what is important is to be able to conceptualise latent processes, some of which will not be articulated explicitly, but may commonly occur across the group. To aim to quantify what it is that they do would be likely to fail in any task of grasping the complexity of the social and psychological processes that may happen. The aim is to have enough of a consistent story from a number of users

of the MCA to get to a point of abstraction – having concepts about the process, theories ground out from the latent concepts that are observed from the data.

2.3.3 Research interviews

The next key component for researchers is to develop an appropriate way of gathering the data. Glaser (2012) says that “all is data.” (p.28), and is by no means confined to in-depth interviews. Nontechnical literature (Corbin & Strauss, 2008) such as biographies, diaries and reports can be used alongside observation and media such as video or other recordings. Some researchers use multiple sources which discuss the same phenomena in a process of *triangulation*. This may assist with trustworthiness or rigour of the data (Corbin & Strauss, 2008). The issue of rigour is discussed later in this chapter.

The two main interviewing methods in qualitative research are *unstructured* and *semi-structured* interviews, both of which can be intensive and are in contrast to general conversation (Charmaz, 2006). Corbin and Morse (2003) favour unstructured interviews reporting that this can provide the richest data. They state however that this method is not for the faint hearted, and can leave novice qualitative researchers concerned about silences and gaps along with the appropriateness of the content and any risks the narrative may pose. Corbin and Morse (2003) found that research reviewing boards were perpetually concerned that qualitative interviewing could lead to participant distress, particularly where the focus is on an emotionally evocative subject. This assumes a narrow view of the research interaction, and that a researcher would be unscrupulous enough to gain the data whatever the cost. Review bodies tend to request safeguards to be built in to the programme of work (such as sign-posting and supervision) to counter emotional risk. Corbin and Morse (2003), stated that in their extensive experience of working with sensitive topics, there had been no reports of adverse effects due to research participation, and in fact

some participants were grateful for the experience of speaking about difficult topics that affected them.

In this study, a semi-structured schedule was used to guide the interviews. This method was selected because it helped to focus the research on the technicalities of applying the MCA. It was also a good way of supporting the novice GT researcher, and, given the brevity of the programme of work, it helped make the data collection and analysis manageable. There are some issues with this method however. In particular, the wording of the questions may not lead to full disclosure of relevant experience and can limit unanticipated stories which may lead to new ideas about the topic (Charmaz, 2006). Given the open nature of the questions, some participants will speak at length about their experiences, but it may be hard to decipher information (or 'noise') from data. Perfunctory answers too can be common and limiting (Corbin & Morse, 2003).

To help manage these limiting factors in this study, a brief critique was written after each interview which reflected directly on what questions were asked, how they were asked, what opportunities were embraced or missed, identification of where further questioning might have helped, and observations about the researcher's involvement and curiosity during the session. This in turn supported subsequent interviews, allowing the researcher to prepare better for questions that previously resulted in a poor response, difficult silences and unanticipated answers. A summary of the narrative and the context of the story were also produced after each interview to help swift recall of the story line and key points, and how these might relate to other interviews. All interview schedules can be found in appendix D. How changes were made to the interview schedule is described in chapter 3.

2.4 Data Analysis

Interviews were transcribed verbatim and subjected to coding procedures. Data were managed using NVIVO 9 (QSR International, 2010), a software package developed to support the analysis of qualitative data in many forms. Each interview transcript was uploaded to the software where it was coded and memos were created. Memos were also created in a hand-written journal. The use of computer packages is not without criticism. Charmaz (2003) is concerned that use of computer technology develops an objectivist approach to the data, putting a distance between the researcher, the participant and the context, and potentially overemphasises coding which may produce shallow analysis.

The method of constant comparison is an integral part of GT. The principle is to compare new data with data already collected and coded to look for emerging patterns, themes, typologies and concepts. Given the vast amount of data that can be produced, there are a number of strategies that can be helpful in making comparisons including various forms of coding, memo writing, diagrams and mapping (Clarke, 2003; Corbin & Strauss, 2008; Charmaz, 2006). Boeije (2002) suggests that the constant comparative method is often poorly explained in research reports, and that this can affect transparency and credibility of the study. Furthermore, that this problem is not one of reporting *per se*, but one of not understanding what is to be done. Comparing each piece of data with what appears to be relevant is suggested by Morse and Field (1998) as impractical, and would cause further problems regarding context, meaning and essentially be reductionist. Boeije (2002) finds the term ‘constant’ one of exaggeration, and that importantly there are ‘moments’ of comparison. She proposed that there should be a planned approach to data comparison and that this should occur in a transparent and systematic way. However Boeije’s (2002) suggestions are inherently pre-emptive and fail to adequately account

for the intellectual creativity (Corbin & Strauss, 2008) that is often required to observe the latent processes that are in the data.

2.4.1 Coding

There are some differences in terminology used to describe coding according to which school of GT one subscribes, however there are similarities across these procedures. This study followed the method of Glaser and Strauss (1968) by initially having open coding, followed by axial and selective coding (see below for details). Open coding consists of line by line examination of transcripts, attaching descriptors to the text that account for what is being said and supports the process of analysis right up to and including category and hypothesis development, and elucidates the core categories. Axial coding looks at the relationships between those categories, as typified by the relational hypotheses. Thus coding is the starting block for hypotheses development. When data is broken down through open coding it is re-grouped into conceptual categories (Glaser, 1992). This begins to tell the story of what is going on in the data, and it supports the researcher in generating hypotheses which attempt to demonstrate how theories apply given the sample and data. The hypotheses can be single (non-directional statements that something might exist), or relational (the direction of the relationship between two or more variables is stated, and is primarily the focus of axial coding). As the coding strategy moves through open and axial coding onto selective coding the hypotheses are tested against further data collected from the theoretical sample (Glaser, 1978). The testing of the hypotheses makes emergent theories richer or disqualify them. These coding strategies are not linear; they are recursive and are in parallel with further data collection and analysis.

In this study, open coding was used intensively in the first four interviews. There were some consistent categories, and it could be seen that cumulatively the narratives set a variety of conditions for specific processes to occur. The open coding along with

use of memos facilitated the clustering of categories into larger, more abstract concepts. For example the staff mentioned human rights, respect, choice, protection and best interests which tentatively appeared to represent the category of ‘ideology’. Axial coding continues the intense focus of analysis around the categories which are developing (Strauss, 1987), and supports knowledge and understanding about how the categories and subcategories might relate, promoting hypotheses development. Focus around these categories and, importantly, the hypotheses, led to changes in the interview schedule to assist exploration of promising questions that arose from the previous data and became phase 2 of the data collection.

Selective coding occurs when subordinate and subcategories link coherently (Strauss, 1987) and thus was the point in which new interview data validated (or could have potentially challenged) the hypotheses. Hence, selective coding allowed for the initial tentative categories developed in Phase 1 to be refined and confirmed as substantive categories, in parallel with axial and selective coding in Phase 2, which helped refinement of the hypotheses, theory and model. Thus open coding supports category development, and axial and selective coding supports theory and model development, primarily through hypothesis testing. For illustrative purposes Table 2 shows an example of open coding.

Table 2: Example of open coding

Transcript	Open code
Researcher: Can you tell me what factors help you manage this part of your job?	
Participant: No... I can't there's nothing that springs to mind. I'm not even sure what training is available. I could do with a bit more I think.	Lack of support Need for more training
Researcher: because I was just kind of thinking about what helps you or facilitates you doing it?	
Participant: I suppose I can... well I can just go back to my peers. I don't have a problem in trying to ask somebody who is more knowledgeable.	Peer support Asking others is not shameful Others are more knowledgeable

There were only two distinct phases of data collection for this study, with the last two interviews (conducted using the same second interview schedule) focusing more on the relational hypotheses, which added no new information to the understanding of staff experiences.

2.4.2 Memo writing

Memo writing is a critical part of the process of grounded theory. It forms part of the data analysis and should support the researcher's thinking, understanding and development of the programme of work. Memo writing was used to explore ideas about what was happening in the data and what else the researcher might want to know. Memo writing during this work became a way of focusing on concepts and

processes which were latent or more abstract. The coding and memos served to help the tentative development of a visual model which may explain what was emerging from the data. This was a work in progress, supported through supervision meetings where the data and coding were examined to assess whether what was emerging could also be seen by others, and it also helped draw attention to issues that may have been missed. Table 3 shows an example of a memo showing the researcher's thoughts on an issue.

Table 3: Example of a memo

Memo - Faith in others Participant Number one is mindful that she might not be making decisions in the same way as colleagues "I'm not sure how different clinicians on the team would use that. I mean we generally always have, we generally have got a value base the same as each other that everything we do is very person centred... So we generally do work along that way but I couldn't talk for another clinician as how they work it out ... in their heads." So earlier she talks of referring to peers and the team for support and decision making, yet she isn't certain of how they arrived at their decisions. She later stated that the framework was 'safe' and something that she was confident her team were all using well, but 'outsiders' didn't. There's variation in who knows what. Moving on from this, if she can't be sure how her team are making decisions than how does this fit with her sense that decision making is a team/collaborative effort? How does she know they're right? Blind faith?

Pages of the handwritten memo journal created in this research process can be found in appendix E.

2.4.3 Theoretical saturation

Saturation is a term often used to signify that there is enough data to support concepts and develop theories and where adding new data offers no new insights. However comparing descriptions of units can be endless. One difficulty is that other readers will often find a new angle to be considered i.e. it is not possible to cover all

of the bases all of the time, (Glaser, 1992). Bowen (2008) suggests that the key factors that support saturation are the constant comparative method (where further layers of evidence are added to verify the theory) and carefully selected purposive sampling. Bowen (2008) also stated that triangulation of data is important, but that would suggest interviews alone may not be sufficient and that is not the case. It is also important for the researcher to be proactive in negative case analysis (Bowen, 2008), being vigilant to data that do not support theories or is in contradiction to other evidence.

In this study, data appeared to neither challenge the hypotheses nor offer new insights by interview 10. Interview 11 further provided information that substantiated the categories and hypotheses and, on consultation with the supervisor, theoretical saturation was understood to have been reached.

2.4.4 Validation

GT (as with other qualitative methods) could come in for criticism for being too subjective. A novice researcher may be too keen to develop a theory and not take issue with data that does not fit so well. Despite the fact that there is structure to the method and data analysis, it remains that researchers will need to evidence their processing of data in a way that satisfies the need for scientific rigour. Glaser (2012) stated that researchers appear consumed with “the worrying accuracy” issue (p28) that can lead to ‘descriptive capture’ rather than conceptualization of a theory. In the case of GT, rigour is about demonstrating the credibility of the theory through a process which is testament to the trustworthiness of the data. Glaser and Strauss (1967) addressed this by using different types of data to triangulate their sources thus strengthening dependability of their findings. Bowen (2009) suggested that an audit trail is one way of managing this aspect of the research. This requires a transparent, systematic demonstration that can account for what the researcher did,

and the thinking that drove those procedures and developed the programme of work. Supervision supports this process by keeping an agenda which returns to the data and how that develops the concepts, theories and models, further aiding transparency (Bowen, 2009). Transparency can be achieved through detailed illustrations of each stage of the programme of work; making available the interview schedules, transcripts, coding, and describing development of the initial framework and tentative models, and the progression towards a model that describes theories which may explain the processes. Thus clear evidence of how the categories, frameworks and models were developed and how the evidence was managed are key issues to demonstrating credibility (Cooney, 2011; Elliot & Lazenbatt, 2005).

Supervision was used to support validation and transparency. Regular meetings with supervisors included the opportunity to examine transcripts, critiques, summaries and coding in order to ensure that what the researcher was understanding and coding, could also reasonably be selected by others. This also limited the potential for a distorted reading of the data. Supervisory meetings were also the place to discuss researcher reflexivity to address epistemology and issues of subjectivity and bias and to share stage by stage the development of the theoretical framework and models from the coding, thus further aiding transparency.

2.4.5 Supervision

There is a need for supervision or mentoring to support the research process of GT, (Strauss 1987; Stern, 1994; and Melia 1996). In this programme of work, supervision was comprehensive and consistent throughout. Both supervisors have respected academic records and specialise with working clinically with PWLD. One supervisor (JW) has particular expertise in GT. Supervision was the appropriate place to check out if what the researcher was observing could also be recognised by others and to check out assumptions and interpretations that were being made from the data. This

was particularly useful at the coding stage and development of the first four interviews. Coding items line by line from a transcript can take the researcher so close to the data that it almost becomes distorted. One interview raised ethical issues precisely because of this distortion; context and meaning had become blurred as the descriptive capture and concern for accuracy became prominent. It took the relative distance of both supervisors to re-assess what was said in order to restore context and meaning. This also helped the researcher maintain her methodology in line with her epistemological position and therefore 'co-piloting' was an important part of the research process.

2.5 Reflexivity

Reflexivity is important to the qualitative research process as it is the tool that researchers use to make explicit their awareness, experiences and expectations, not just about the topic being explored, but beyond the academic and professional and into their own social identity (Neill, 2006). This process aims to limit researcher effects and any potential distortion in the sampling and data analysis (McGhee, Marland & Atkinson, 2007). This section provides a personal statement in which the researcher's experiences and expectations are outlined. At the end of the thesis (section 4.5) reflexivity is re-stated demonstrating how the experiences and expectations of the researcher were managed during the research process.

2.5.1 Reflexive statement

The researcher's previous work has included studies about service development, particularly examining mental health service needs of vulnerable populations and identifying the gaps that may exist. The researcher is passionate about safeguarding human rights and challenging discrimination in access to healthcare, and considers

herself to have some clear political and philosophical beliefs. More specifically, the researcher holds a socialist political and philosophical ethos, believing in community, and socially funded, non-profit making health, education and social care systems. The researcher also believes in equity over equality; that developing a fair and equitable society which accounts for individual differences but allows people access to society in a way that similar outcomes can be achieved is preferable to promoting equality, in which people have access to the same society, but the outcome is limited by individual differences.

Prior to her learning disability placement on the D.Clin.Psychol programme, the researcher had little experience of working with PWLD. The researcher enjoyed this immensely and found working with PWLD was a prominent career choice on completion of the doctorate. The researcher has neither directly nor indirectly used the MCA in her research or clinical roles despite occasionally raising the issue about capacity in clinical supervision. Discussions about capacity generally resulted in the supervisor taking the position that assessment of capacity was not required, which the researcher agreed with.

Through clinical and academic work, the researcher has come to understand some of the difficulties that PWLD can experience when accessing healthcare. At times healthcare professionals themselves have been the gatekeepers to equitable care, and some healthcare professionals have responded with cynicism about the MCA. This may lead to some scepticism for the researcher during the coding and analysis of data about what the participants may be reporting. In particular the researcher expected the MCA to be an unwelcome part of the care process and for staff to state that the use of the MCA was problematic, that it added to their workload or compromised their role (i.e. was an obstacle). Understanding that the researcher's beliefs may differ to those of the participants, it will be important for this to be limited

to ensure data is managed objectively. The researcher will reflect in the discussion her position in relation to the data given her prejudices. The use of field notes, memos, and maintaining a good, regular working relationship with supervisors were designed to counter subjectivity and bias.

Chapter 3

3.1 Analysis

The aims of the research were to explore how staff working with PWLD make sense of and use the MCA, and to look at factors which may influence staff's use of the MCA in clinical practice. By using GT methodology the study hoped to capture factors that facilitate staff in their role, and in particular examine the social processes involved. Data analysis was an iterative process. The first part of this results section explains phase one of the data (the first four interviews) and the subsequent coding and analysis from which a tentative theoretical framework of the early categories was derived. One key objective of this phase was to identify the main areas of concern or significance to the participants. Appendix F provides an alpha-numeric list of the nodes created in NVIVO from open coding. Appendix G shows how the nodes were first thought to cluster into tentative categories. This study followed the process of GT as proposed by Glaser and Strauss (1967), which emphasises the importance of having the process driven by hypotheses development and testing. It was therefore important (not just to be authentic to the methodology, but to support the audit trail) that the category development was able to reflect the emergent hypotheses. During the development of the hypotheses, the first tentative clustering of codes appeared less useful, and was revised in light of the emerging single hypotheses, and supported tentative development of relational hypotheses. The revised clustering can be found in appendix H. As the main aim of the study was to develop a model to account for participants' experiences of using the MCA, the analytical process was driven by developing, testing and refining hypotheses throughout.

The second phase of the study involved interviewing seven participants. The interviews were designed to explore the relational hypotheses further. As constant

comparative analysis continued, it was felt (on consultation with supervisors) that by interview 10 and 11 no further information was being added nor alternative viewpoints offered. It was intended that that there would be a third phase to focus on refining the model through selective coding and focusing interviews around these areas explicitly. This was not needed however, given that the participants were not providing new data. Coding became selective by the nature of the focus of the interviews, and so it was thought that theoretical saturation had been achieved as analysis was deemed to be sufficiently complete at the end of phase two.

When writing up a GT study, there is often a tension in deciding where analysis ends and the discussion begins about what is happening in a broader sense (Strauss, 1987). This section explores the codes, category development, development of hypotheses, and building of a model from the narratives. Descriptions of what is occurring in the data will be drawn out in richer detail in the discussion.

It is also important to note what it is that participants mean when they talk about decision making. The process of assessment of capacity is different than the determination of best interests (McDonald, 2010), yet both are brought to attention by staff by means of their own involvement in decision making. The sequence of decision-making in the normal process of events is that i) a question arises about capacity; ii) the staff make a decision to assess formally or not; iii) if an assessment is done, a decision is made about whether the individual has capacity or not; iv) if not, a decision about what should be done in the individual's best interests is made. The process is complex and incorporates several decisions. Despite trying to get clarification, at times it was difficult to discern what decision at what stage participants might have been referring to. It may have been a difficulty with the interviewing that at times the researcher's confusion may have mirrored the staffs' confusion, as all of the 'sub' decisions seemed to merge at times into 'the decision'. This suggests that the process as described above is not always clearly delineated in

the minds of the staff. What is further unclear from the participants' narratives is if they (individually) make a decision about capacity, or whether they have an idea about what they believe the outcome to be but take it to the MDT where a formal decision is made about capacity. What is clear is that what is to be implemented in the service user's best interests appears to be done by the MDT or in joint consultation with other care or social service stakeholders. Thus there are a number of places for staff to be involved in decision making but as this was not well clarified in the interviews, it is a limitation of the study that little is known about who is really responsible for any decision made.

3.2 Phase 1

This study had two distinct phases of data collection. After the first four interviews (using interview schedule one) several common themes were identified, which led to provisional hypotheses developed for testing in phase 2. This section presents the most salient of those common themes and their associated hypotheses and reflects the process of developing the hypotheses to be tested.

The participants' narratives in the first four interviews told of difficulties in using the MCA, and factors or strategies that may affect the way they work. Some common difficulties were beyond their control such as healthcare professionals external to the LD service (including GPs and surgeons) not understanding the MCA and making requests that disregarded or went against the rights of the person.

> *"We get a lot more referrals from GPs and from other health professionals asking that we do things that go against the Act."* – Anna, 319-320

> *"she wouldn't have been able to make the decision herself, so obviously the people around needed to be consulted but he [the doctor] sort of didn't seem to think that he...even had to go through that process and it was alright for him just to do that"* – Cath, 234-237

Provisional hypothesis (PH) 1: *There are emotional processes and moral evaluations involved in the use of the MCA*.

In addition to this there were frequent stories of discrimination and histories of abuse and trauma which the participants of this study were prepared to safeguard against and champion the rights of the service users they work with. Each participant has chosen to work with PWLD and from this point their role as professional helper may be geared towards protection (either of the individual or their human rights). Other consequences of working in healthcare may include developing/maintaining their own self esteem. Data suggest that psychological motivation (emotional processes and moral evaluations) behind their behaviour may affect their use of the MCA.

> *"To protect the most vulnerable people in our society... It gives us that evidence base that we need to work on. Yes I just really like it. I'm quite passionate about it".* – Anna, 424-426[2]
>
> *"where it's not gone the way I would have personally hoped, and it's been something that's put somebody at risk."* – Ben, 312-313
>
> *"It's there to help you make good decisions, decisions that benefit service users"*. – Debbie, 441

Provisional hypothesis 2: *There is a level of subjectivity to applying the MCA*

A further common narrative that emerged was regarding the assessment and decision making process. These are separate aspects (deciding an assessment was needed, completing an assessment and deciding on the outcome). With respect to the assessment process, three of the staff appeared to have 'informal' and 'formal'

[2] Numbers represent start and end line numbers in the transcript.

approaches, whilst one, Cath, appeared to just take a formal approach. It was difficult to understand what was happening here so a tentative hypothesis about there being *a level of subjectivity to applying the MCA* was developed with a view to exploration during further interviewing.

> *"You're constantly assessing whether that person's got capacity... sometimes you'll do that informally through general discussion with the person, with the carers. And then other times when an intervention is necessary, then it becomes a more formal process".* – Anna, 114-117

Provisional hypothesis 3: *Peer support is important to the assessment and decision making process.*

The decision making process with respect to capacity was largely a team effort, and those decisions that may have been taken by the interviewee alone were checked out through supervision or peer support. Common to all four interviews was the value of peer support, leading to a further single hypothesis that *peer support is important to the assessment and decision making process.*

> *"That's one of the wonderful things about our team, y'know. You can walk around and say 'have you got two minutes... can we talk about...' You never hear 'no.' ...so yeah it's one of the topics that's always discussed. We talk about it quite a bit."* – Anna, 104-106

> *"I could go to anybody downstairs and say y'know "I don't know if this person's got capacity or not, these are the things they're saying, do you think I needed to do or have done this or that" and you could grab anyone and anyone would be able to help you."* –Debbie, 384-387

Provisional hypothesis 4: *Applying the MCA involves professional risk taking*

The issues described above (subjectivity and the need to seek support from others) led to exploration in the data of what risks may exist for staff and how they might manage them. Ben and Debbie had concerns that their use of the MCA may lead to negative professional consequences. As the MCA is part of the legislative framework of the NHS, there may be a risk of being exposed as clinically incompetent, or negligent in the application of the Act. There is a range of possible negative consequences to getting the assessment or decision wrong which may include not being respected by colleagues or other professionals, or even legal sanctions. From this the hypothesis *Applying the MCA involves professional risk taking* was developed.

> *"as a qualified nurse it's probably get me in a lot of lumber to get it wrong."* – Ben, 295

Provisional hypothesis 5: *Applying the MCA involves psychological risk taking.*

Further to this there may be other effects due to the risk of making a wrong decision or being discovered to have inadequately managed the task. Debbie and Anna demonstrated that there may be some cost to self esteem or feelings of competence hence the development of the hypothesis *Applying the MCA involves psychological risk taking.*

> *"that's when you get that heightened sense of anxiety of like "Oh God this is like formal, and people are going to scrutinise it."* – Debbie, 208-209

Thus the narratives from the first four participants appeared to speak about psychological processes, subjectivity and professional and personal risk taking. In

addition to these, further aspects were about factors important in the management of and influences in the use of the MCA.

Provisional hypothesis 6: *Training is important to the use of the MCA*

In particular, the issue of training in the use of the Act showed some variance across the group. No two people were trained in the same way and there seemed to be a suggestion that training did not just provide knowledge, but perhaps was involved in other processes such as contributing to the development of confidence and competence. Whilst it was not possible to state how much training was a factor from these few interviews, Ben's narrative suggested that he had the least training and he appeared the least confident to the point that he fails to actively engage in the use of the MCA, preferring others to lead on assessments, with his role being to supplement evidence.

> *"Researcher: Can you tell me about any problems you've encountered when conducting an assessment for capacity?*
>
> *Ben: erm... no...I can't, as I say mainly it's been led by someone else." – Ben, 309-311*

These aspects required further exploration in future interviews, but led to a tentative hypothesis that *training is important to the use of the MCA*.

Provisional hypothesis 7: *People may use strategies to reduce the risk to themselves.*

Given that there may be some issues people find difficult when applying the MCA, the narratives suggest that *people may use strategies to reduce risk to themselves*

and thereby increase confidence or perceived competence. These strategies may include simplifying their understanding, simplifying strategies to address the task, or avoidance of pro-actively participating in the task.

> *"There are easy read versions of the Act for carers, there's easy read versions for patients. I like the easy read versions, and I tend to work generally on that stuff."* – Anna, 99-100

> "*I've got this little BPS leaflet that I've got by my desk, just to sort of, to have."* – Debbie, 110

Provisional hypothesis 8: *The significance of the decision to be made influences the use of the MCA.*

The first four participants also spoke about factors which affected their decision making. Ben and Cath suggest that the types of decision to be made (or how it might affect the service user) are considerations in their assessment and to some extent the bigger the decision (e.g. safeguarding), the easier it is to make decisions about capacity: *The significance of the decision to be made influences the use of the MCA.*

> *"I'm not making a decision on... whether she's picking... red or blue shoes or something."* – Ben, 262-263

Provisional hypothesis 9: *Level of disability influences the use of the MCA*

Similarly, service user factors such as severity of LD or communication problems appear to make for an easier assessment. Hence a hypothesis about the *Level of disability influences the use of the MCA* was developed.

> *"Has not got capacity... she has a severe learning disability."* – Ben, 217

"The person, did have a severe learning disability so... she wouldn't have been able to make the decision herself."- Cath, 242-245

Provisional hypothesis 10: *Family involvement can affect decision making.*

Other factors that were common to the four interviews were about knowing the family or having family involvement and having some contextual understanding of the person. Anna and Cath were aware of family/carer desires for their service user and it was suggested that this had a bearing on how they performed the task of assessment so the following single hypothesis was developed: *Family involvement can affect decision making.*

"Dad had gone to the GP and said "I'm worried, the service provider are asking for bloods, I don't think she needs them, what shall we do?" – Anna, 198-199

Provisional hypothesis 11: *Understanding contextual issues about the person affects the use of the MCA.*

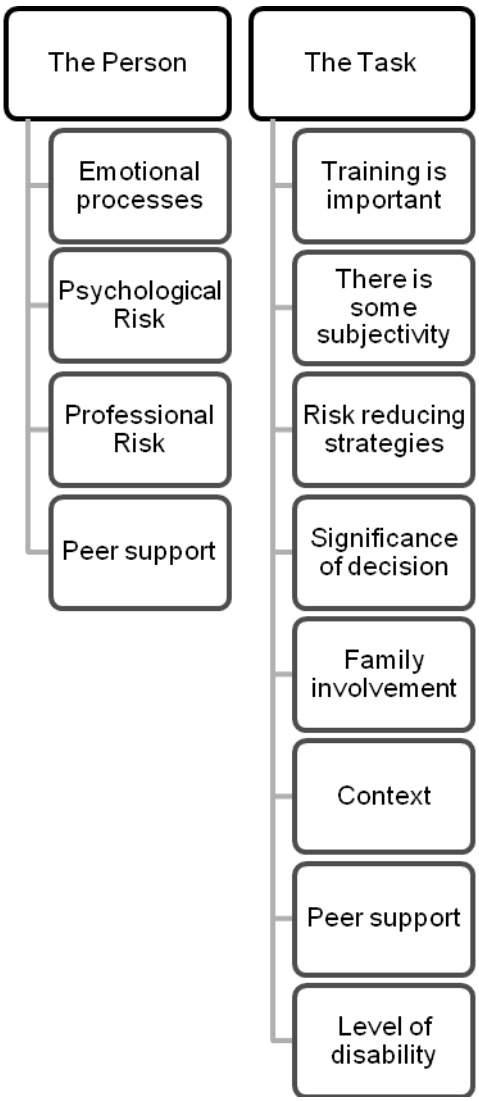
Furthermore, knowledge of a history of abuse, trauma or prejudice, or where there is likely to be implications to the life of the individual could affect the use of the MCA. All four participants made statements relating to this: *Understanding contextual issues about the person affects the use of the MCA.*

"She's got a history of not liking bloods taken. Extreme, extreme distressing situations in her past, being held down as a child... being really hurt and bruised afterwards in her home environment. Really quite like traumatic stuff for this young person. So that we were aware that any decision that we made was going to probably be quite traumatic." – Anna, 183-187

> *"I've had a gentleman in hospital recently that had a catheter fitted. Obviously the doctor decided he had that catheter fitted but what they didn't realise was that the implication on the rest of his life that he now couldn't do hydrotherapy... so there was further implications which he, maybe if a wider range of people like myself and his carers were considered they may not have made the same decision."* – Cath, 846-851

These eleven provisional hypotheses appear to group in two ways; relating to the person (staff) or relating to the task. Peer support is the one hypothesis which appears in both categories.

Figure 1: Groupings of the provisional hypotheses.



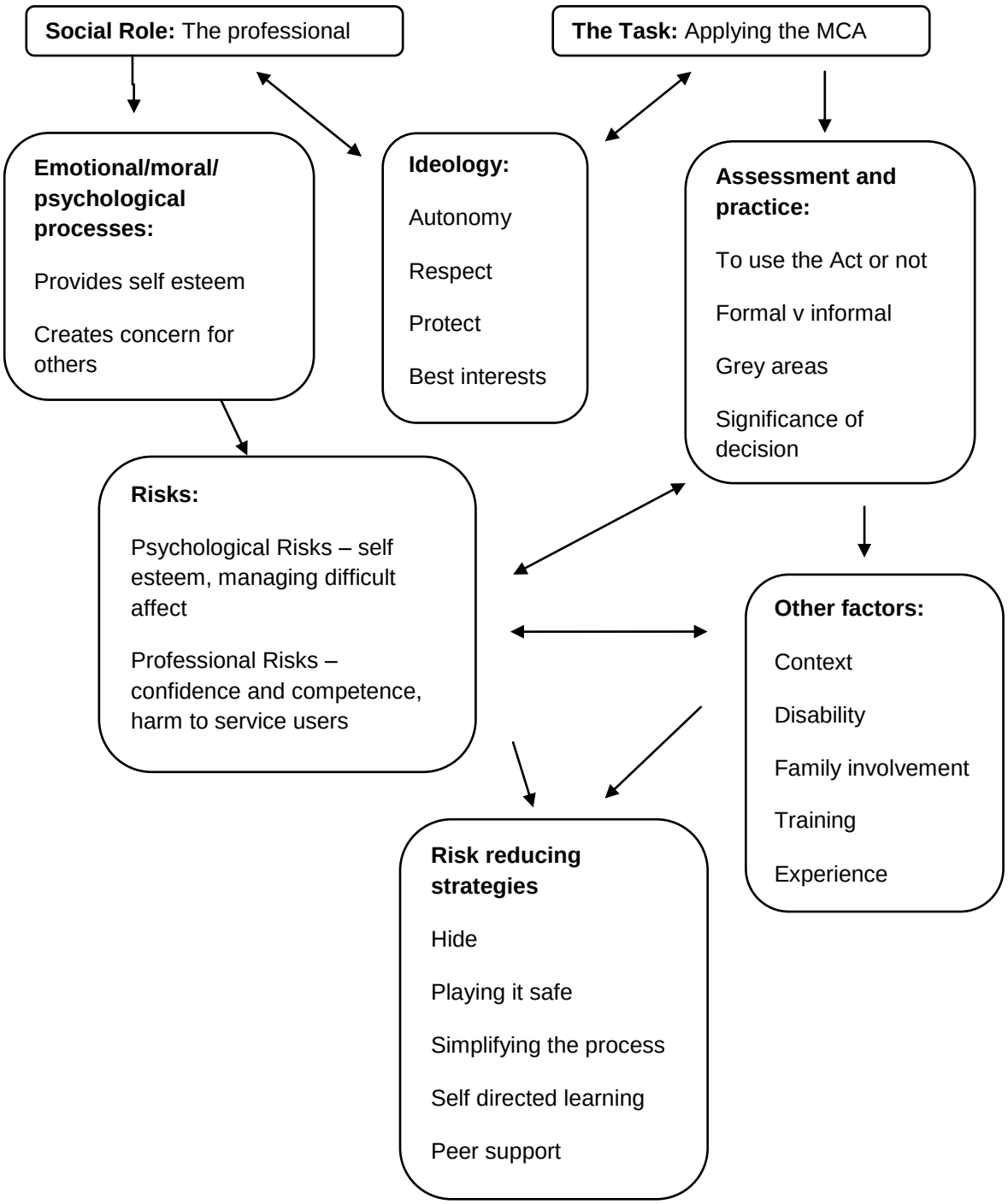
Each transcript was read and re-read a number of times, not just for the purpose of coding, but to create summaries about each person. This helped to position their story in the context of their experiences and enabled the development of relational hypotheses linking from the provisional (single) hypotheses. Eleven of these relational hypotheses were drawn out based on data from coding, narrative and summaries. These are presented below:

1. Experience of applying the MCA (time and number of assessments) improves confidence
2. Peer support improves confidence in applying the MCA
3. Education improves confidence. (Definition of education: self-directed learning or formal support seeking i.e. literature, websites)
4. Training improves confidence. (Definition of training: formal teaching provided or contracted by occupational or educational establishments specifically relating to the MCA)
5. Experience improves competence
6. The significance of the decision to be made can increase the ease of assessment
7. The more profound the range of service user difficulties the easier decision making process is
8. Decisional grey areas increase the risk to the participant's professional role
9. Decisional grey areas affect the participant's psychological processes
10. Lack of performance management increases confidence
11. People with many years experience are less likely to make 'informal' assessments

By the end of the first four interviews, there was a tentative framework developing. Figure 2 shows how the coding from the narratives appears to map out. These are in line with the first clustering of codes (appendix H). This early model prompted further questioning about what might have been happening in the data, and led to the reorganization of the codes as in appendix I. This project is about how people make sense of and use the MCA. Glaser (1992) stated that attention needs to be paid to basic social and psychological processes involved. Further interviews and

subsequent data analysis therefore needed to pay attention to is what was really going on behind the narrative and abstract theories from the latent processes.

Figure 2: Tentative diagram showing emerging observations from the first four interviews



3.3 Phase 2

After the micro-coding of the first four interviews and development of the tentative framework, the interview schedule was altered to focus on the emerging key issues. The interview schedules can be found in appendix E. The second phase of interviewing focused on a number of areas to enable the hypotheses developed in phase one to be tested and refined. This included an examination of what working in healthcare means to the participants; what the consequences of decision making could be; an understanding of the significance of training, experience confidence, and feelings of competency; about the distinction between formal or informal use of the act; inquiring about managing difficulties such as grey areas; and also the function of peer support.

The aim of the subsequent interviews, (along with data from phase one) were to test the framework and allow examination of the relational hypotheses across the range of participants. Hence attempts were made to recruit purposively, with participants selected based on role or number of years working with PWLD (see Table 1). Five participants had worked for less than six years with PWLD, and the remaining six participants have worked over 20 years with PWLD. The majority of staff are Specialist Learning Disability Nurses working in the community. This is discussed further in section 4.4, study limitations.

3.3.1 The relational hypotheses (RH)

RH 1: *Experience (time served and number of assessments) improves confidence*

The participants showed some variation in how many assessments they completed (although explicit figures were not obtained). Those who were more likely to be involved in supporting or providing interventions (such as blood taking) appeared to

use the MCA more frequently. Time (number of years working) was less of an element across the groups because three of the participants who had worked with PWLD for less than six years were involved in a high rate of assessments. It seems that what matters to confidence is practice (hence experience).

> *"I do feel really confident to be fair"* – Cath 317
>
> *"I mean I've done I've done quite a lot of assessments"* - Cath 343

> *"And practical use. 'coz the more you use it, the better you become at understanding its processes."* – Harry, 147
>
> *"I have to say that my understanding of it has developed more in practice rather than in theory...I don't think it means as much until you start to put it into practice."* – Joanne, 43-44

RH 2: *Peer support improves confidence*

Peer support was recognised by all participants as important to their role and the use of the MCA.

> *I think that it just gives you the confidence to go and do the assessment <u>with confidence</u> rather than "oh my god, what am I doing?"* – Fay, 202-203 (her emphasis)

The function was also under scrutiny in relation to this hypothesis. It appears that peer support helps staff with the process of using the MCA and also with checking the outcome.

> *"peer support gives you a bit of a sounding block really...Peer support doesn't necessarily just say this is how I want to use the act, do you think that's OK? It's about giving you that opportunity to say this is the reason I'm thinking about using the*

act, and these are the reasons why I think this person may not have the capacity or does have the capacity, this is the decision, how do you think I can put this across in a way that's going to help me identify whether this person can understand and retain that information. It can also be about saying, I really think that's a very complex idea, how are you going to explain that? And you know, just kind of thinking, I'm not really sure myself, so sometimes it's like going away and saying well actually I know somebody who's done this before, and finding out who, who can maybe help you better." – Harry, 125-133

"I think also afterwards and getting feedback from peers and saying 'we did make the right decision, it was the right thing that occurred'." – Joanne, 246-248

"Well it can be useful to sort of talk about things before hand. So you know that you've got your head on straight...but then once you've done it to maybe take it back and sort of a de-brief" – Gina, 204-206

A common feature is a sense of cohesion that peer support brings. Variations of the phrase 'we're all singing from the same hymn sheet' were used to show that they were in line with their peers and that collectively they were doing the same thing. It may be that this helps to manage the responsibility of decision making (a professional risk), or to manage feelings associated with the implications of the act (emotional processing).

"Everybody else is doing the same so it just gives you that confidence that we are all singing from the same hymn sheet and we're doing the same thing." – Fay, 203-204

"I think, as a team, we're all pretty on the same wave length when it comes to that." – Gina, 62-67

RH 3: *Education improves confidence. (Definition of education: self-directed learning or formal support seeking i.e. literature, websites)*

Two of the first four participants (Anna and Debbie) sought educational material to support themselves in their role. Ben, who was less inclined to participate in MCA assessments was developing his learning in an *ad hoc* fashion, and was not proactive about seeking knowledge. Over the course of the other interviews, only Gina took to seeking to simplify the process for herself (like Anna, she accessed the easy-read material provided for service users and carers). What was more common amongst the participants was having access to resources and documentation that they could be expected to consult when applying the MCA.

> *"Researcher:...what factors... help you get the job done?*
>
> *Gina: I don't know really, I just do it. I suppose my easy–read thing. Having the information available really because you don't do that many maybe, so it's just having stuff available just to remind yourself. And we've got a policy as well"* – Gina, 193-196
>
> *"it's a big document so every day it's on my desk, it's always there and I've got it on my desk. I can always put my hand on to it... the trust policy and I just work through that every time I get ...something that needs to use it. I just follow that, the guidelines. So I feel pretty confident in using it."* – Ella, 147-151

RH 4: *Training improves confidence. (Definition of training: formal teaching provided or contracted by occupational or educational establishments specifically relating to the MCA)*

This hypothesis was developed from the stark contrast of Ben's lack of training compared to the relatively detailed training received by Cath and Debbie. Further exploration of what training people had received did not appear to map well onto their confidence. Nobody spoke about it being either a facilitating factor or a hindrance to

their practice. Some, such as Debbie and Gina said that they would like 'refresher' courses, but on the whole training *per se* was not identified to be important to the confidence in using the MCA.

RH 5: *Experience improves competence*

This hypothesis was developed from noticing how different Ben's experiences were compared to the other three participants in phase one, and how he seems to be less comfortable than the others in using the MCA. This is not to say that Ben was *incompetent*, but it did appear that his opportunities to become competent at the task were limited. When the other participants were asked about this issue, only Joanne stated that experience improved her competence. For the others, it was a range of other factors including supervision; knowledge and education; knowing that the service user understood what was happening, that they felt contributed to a greater sense of competency. The common factor is that they state that their competence is in part due to some defining action which appears to reassure them (thus perhaps also providing some confidence). Ella stated that she felt competent because there had not been any 'comebacks' about her work. She endeavoured to show due process, be transparent and justify what she had done, and feels as a result no-one had passed comment on her work. She felt self assured that she must then be doing something right, which is similar in some way to Harry in that he feels competent if he can justify his work.

> *"Personally I feel competent...I've never had any come back...I've always followed procedures and documented it and made sure everything was on record."* – Ella, 170-171

> *"It's about backing it up. It's about coming away and discussing it with the individual, It's about, I suppose, if I'm working with an individual and I think they have got*

capacity, it's about going, making sure I've gone over that again, just say, can you tell me what I've asked you?" – Harry, 233-236

It may be that experience (number of assessments) is less likely to be a major factor in the participant's feelings of competency, and more that it is about feeling secure in their processing of the MCA which holds more influence. Kerry also has similar experiences. She felt her competence was driven by her ability to be strong and forthright with others about doing the job properly and getting the process documented.

"I feel that I'm competent one because I insist that there's a capacity assessment informal or formal completed and I feel that I'm competent because I would ensure that that is documented." – Kerry, 187-189

It would appear for her she is reassured by her own ability to make sure others are involved appropriately.

RH 6: *The significance of the decision to be made can increase the ease of assessment*

All participants spoke about interventions that potentially had a significant effect on the service user, be it trauma, risk and safeguarding, or illnesses that are life changing or threatening. At first, Ben and Cath demonstrated that 'major' decisions appeared to ease the assessment and decision making process. But this was not found in other interviews. What did appear was that the significance of the decision made it more important to get it right:

"Joanne: I've had a few multidisciplinary meetings that have been to look at things like whether people should be nil by mouth or whether sort of certain things should be introduced to their eating and drinking and because there's more of a consequence in terms of physical health then it feels like a bigger decision almost.

Researcher: OK so the size of the decision is quite important?

Joanne: Yes, or what could be the consequences if you make the wrong decision maybe." – Joanne, 81-87

Another angle on this hypothesis is that Ben, Cath, Gina, Fay, Harry and Iris all had an appreciation that the MCA is not applied to *every* decision made in a person's life. There will be times when consent is implied because the service user is not resisting, and to this end, it can be the behaviour of the service user or the need for an intervention which act as a trigger to the use of the MCA.

"If there comes an issue, then I would then look at the look at using the mental capacity act cos it becomes an issue around capacity. Like most people, it's only like if something comes up, like if they're going to be moved." – Fay, 180 – 182

Cath: "I suppose sometimes we've got to be mindful...that's almost like one of the things, sometime I sort of query myself with is if somebody like 'accepts' so if somebody's accepting of ...going to a GP, I mean you go to a GP with somebody to have a physical health check, so they do a blood pressure temperature and everything else but there's no Mental Capacity Act assessment done for that because the person's willing

Researcher: 'Cause they've attended

Cath: 'Cause they're not resisting basically." – Cath, 937-946

Given that to use the Act or not is a decision in itself, it lends weight to the idea that when there is a need which triggers the use of the MCA, the decision may have significant consequences for the service user – and getting it right becomes very important to all concerned. This may be a key factor which influences the use of the MCA.

RH 7: *The more profound the range of service user difficulties, the easier decision making is*

Ben, Cath and Iris commented on the severity of the learning disability, and how this compromised decision making. However other participants did not mention this as a factor that may facilitate decision making.

RH 8: *Decisional grey areas increase the risk to the participant's professional role*

Once a decision to use the MCA has taken place, making further decisions about whether someone has capacity involves a number of factors. This means that assessments can be complex and not clear cut. Debbie strived hard to gather evidence to support her assessment at times of grey areas for fear of either not doing right by the person or being exposed as in some way incompetent. Cath appeared to use a strategy that ensured she avoided 'grey areas' (so all assessments resulted in a 'no capacity' decision). The need to use strategies to manage grey areas may be testament to the level of risk that the making a wrong decision might pose. Amongst the other participants Fay, Gina, Iris and Joanne managed grey areas by using the multidisciplinary team (MDT); a collective response to decision making. Interestingly, Ella, Harry and Kerry seemed to follow Cath to a certain extent; grey areas (about

whether a person has capacity or not) are perhaps more likely to result in best interest decisions (essentially 'no capacity'). This may be because they are perceived to be safer. Whom this safety feature is for, the staff – to protect them from wrong doing, or the service user – to protect them from risk of harm, is less well understood. It could possibly be an approach that looks for a 'win-win' situation.

> *"I think...you manage the assessment based on the need. Obviously the act gives you some kind of leeway around emergency type treatment where you think, you know, this is significantly going to impact on you, but where that's not the case, obviously those grey areas don't become light overnight, and it may well be that those grey areas are always going to be there, but I think fundamentally with, if you've got a situation where you've got grey areas it becomes a best interest decision."* – Harry, 317 - 322

> *"We should pre-empt what could go wrong*." – Kerry, 257-258

RH 9: *Decisional grey areas affect the participant's psychological processes*

Given that there may be evidence that a best interest decision may at times be 'safe practice' as a preferred method of managing grey areas, what may also be important is how the risks, or managing them, make the practitioner feel. As above, Cath and Harry may feel safe in their strategies about grey areas, hence self esteem is preserved. Debbie fears wrong-doing either on behalf of the service user or that her self esteem and credibility will be affected. It may be that some staff prefer best interest and team decisions because it is emotionally and professionally safer. Given that all staff provided examples of situations that pose a risk to the health and well being of the service user, and that the staff do appear to have a strong, compassionate moral endeavour to support their charges it is reasonable to expect

that ensuring appropriate care is provided feels better than letting a person with capacity make an unwise decision (which may bring greater risks).

> *"because you didn't come into the job for people to make unwise decisions. You want to protect people don't you? It's very hard to allow people to be..."* – Fay, 75-76
>
> *"I think the Act is quite clear that people have the right to make unwise decisions, as do you and I. But it's just swallowing that" – Fay, 97-98*

> *"She's quite vulnerable in terms of sexual health, and also in terms of finances because she makes unwise choices...she's put herself in very risky situations meeting blokes and you just sort of think "agh"!"* – Cath, 542-545

> *"Harry: I think that's probably a difficult thing for most agencies who have a supportive, caring role where the, the right to make those unwise decisions*
>
> *Researcher: But why is that difficult?*
>
> *Harry: That's a paternalistic issue...I'm looking after you, I'm looking after your health and your health is everything"* – Harry, 160-165

Ultimately, grey areas could swing one of two ways; a decision of 'no capacity' in which a best interest decision is made (safe), or a decision of 'has capacity', and the person is free to make an unwise decision (unsafe). Watching a service user make unwise decisions that may be harmful was identified as difficult by the participants. This suggests a strategy of erring on the side of safety – sometimes the participants prefer to set safety as the premium. It is not known if they make assumptions and not test for capacity, or test and in order to justify that the person has 'no capacity'. This cannot be speculated on further and would require more research, although it might

be difficult to capture explicitly as it would mean that staff would have to admit to going against the principles of the MCA.

RH 10: *Lack of performance management increases confidence*

When asked about performance management, staff did not state that having no means of checking their work improved their confidence. However they did state that the process is required to be justified to others which to some acted as a means of performance management. What can be understood from the use of the MCA is that aspects of the application of the MCA can be subjective, so much so that consensus decisions are frequently made based on a body of evidence. This process aims to arrive at the most credible decision; there are no absolutes to be measured (i.e. one could never be truly certain about what an individual 'understands'). Performance based on competency (how staff gathered and processed their evidence) or based on outcome (decision) therefore is unobtainable because of the individual nature of each service user's difficulties, circumstances, specific nature of the decision, etc. The best a service could do would be to audit the use of the MCA, and not the actual processing of it. Given that staff have no outcome measures for performance/competency in routine practice, their work remains unchecked unless a serious challenge occurs. It may be then that the *process* is all important, not the outcome hence what truly matters is justifiability – the staff are keen to show they can justify how they have arrived at the decision they have. All of the participants state that they endeavour to check out with others and ensure that their work is documented.

> *"Researcher: So in that way it's monitored because…*
>
> *Ella: Because we normally, -it's very rare there's just one person making a decision in this so certainly with what I have done there's always been someone else involved"* – Ella, 52-54.

"because it's not documented, that's where people lack the evidence," – Kerry, 97

"If a solicitor was to have rang me and sort of questioned me on it then I would have been able to justify the reasoning behind why I'd put the things that I had." – Debbie, 223-225

RH 11: *People with many years' experience are less likely to make 'informal' assessments*

Across the participants, there was variance in who perceived their practice to be informal or formal in approach to assessment. Anna, Ben and Debbie first suggested informal approaches. However Cath did not. Her assessments were always formal and always resulted in a 'no capacity' decision. It may be that experience provides staff with a rubric about what to look for or what to expect - one which is so much part of what they do that they do not recognise or label it as an 'informal' part of the assessment. The remaining participants clarified this a little further. Only Ella (with the greatest length of service) stated that she simply used formal procedures. The other participants recognised, as Anna did, that there is a preparatory approach; that staff are perceptive to the cognitive and communicative functioning of service users before the formal assessment processes begin. They also suggest that formal assessment procedures are likely to be triggered by the need for intervention (as mentioned previously in the hypothesis *the significance of the decision to be made can increase the ease of assessment)*

3.4 The theoretical model

This research aimed to look at the task of using the MCA in routine clinical practice and to examine the experiences of staff to find out how they make sense of and use the Act. Each participant told a tender story, one of care, of safeguarding, of concern and worry, of relationships, battles and triumphs; a humanitarian story. Interviews were conducted at the premises of the service, and the researcher was privy to the offices and work stations of the participants. What was striking was that the participants often had pictures of service users pinned on their wall next to their computer, alongside pictures of their own family members and favourite film stars. Art work and pictures of celebrations with service users were important. They represented relationships, memories, and attachments. It is this attitude towards the people they work with that makes decision making all the more important.

The theoretical model suggests that this is the context within which the staff use the MCA. They use it as a tool for justice and protection of human rights, safeguarding service users against prejudice, abuse and neglect whilst also ensuring that they have optimal opportunities to become involved in their own care. What staff have to make sense of and manage are the risks and threats that exist in applying the MCA. There are professional risks; ones in which staff may be faced with decision making that could compromise their sense of service user safety; or which could mean that they are at risk of making poor decisions that threaten their professional integrity, i.e. they may be challenged by others or be seen as incompetent and face professional or legal consequences. There are emotional risks too. The moral endeavour of working in healthcare means that they have a sense of needing to do what is right otherwise it affects their self esteem. The outcome of decisions can lead to worry and concern about the service user, giving way to uncomfortable ‘parental’ feelings. The risk is that staff’s feelings about service users could compromise the very tool they

have to support their charge. Fortunately, there are a number of strategies the staff engage with which mitigate these risks in order to justify the process and outcome of the use of the MCA. These include teamwork, peer support, documentation, and safe practice. This is the basis of the theoretical model.

All of the participants have chosen to work with PWLD, from the very start of their caring career. Seven were able to make statements about what working in healthcare means to them. Their responses are a testament to a moral endeavour:

> *"I think it's about enhancing people's lives and helping people to overcome difficulties or to achieve things that maybe they weren't able to achieve before, and it's a means of contributing back towards people I suppose, but with no cost as such to the person. So it's not something that they have to purchase privately it's something that's accessible to all."* – Joanne, 36-39

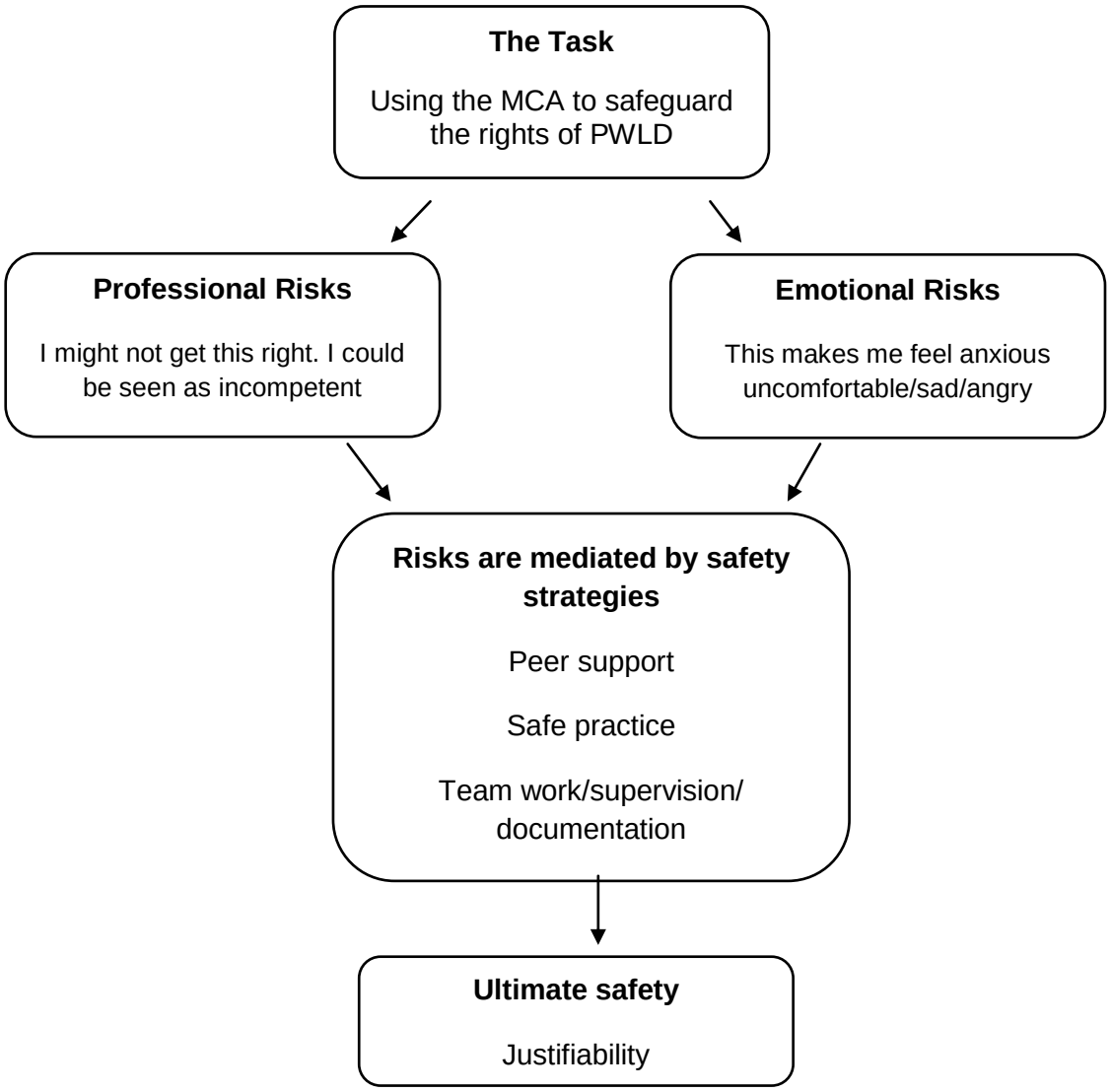
> *"What does it mean to me? Well it means a lot of things. I enjoy the job, immensely. I get a lot out of it when we see people improve and that is the main thing."* – Ella, 27-30

Six participants witnessed the prejudice or neglect around health experienced by the people they work with because of their learning disability. (These issues are in relation to wider NHS services outside of the one they work for). The participants also understood that some service users they worked with had experienced abuse in the past. All chose to share a narrative about making sure that the person was cared for appropriately, that trauma was avoided, that neglect and prejudice was challenged, or that safeguarding worked. They believe that they are championing the rights of the service users they work with.

> *"My last reason for using it was a young man who we felt he needed this hospital procedure and he sort of had the door shut in his face because he had a learning disability ... we were trying to make a case for it through the mental capacity act and best interest for him."* – Ella, 44-48

The processes involved in using the MCA confer a number of risks; professional and emotional/psychological risks for the staff and risks to the service user. Staff felt that there could be professional or legal sanctions, or risk which also impact on the sense of self – they were concerned that their work is viewed as competent by others. A further risk is that towards the service user – some decisions are potentially life changing, and the freedom that comes with being able to make unwise decisions could expose the service user to risks that raise concerns for the staff. The way this appears to be managed is through a number of safety strategies, some relating to managing the task, and some about managing the interpersonal affect. The following model (figure 3) has been developed to bring together the data from the participants in a way that demonstrates how these processes apply across the group. The section following the diagram explains how the data has shaped the model.

Figure 3: How staff make sense of and use the MCA



3.4.1 Core category 1

Using the MCA can lead to **"professional risks".** The hypotheses that drew this out are:

- Applying the MCA involves professional risk taking (PH 2)
- Significance of the decision influences use of the MCA (PH 7)
- Understanding contextual issues about the person affects the use of the MCA (PH 9)

- The significance of the decision to be made can increase the ease of assessment (RH 6)
- Decisional grey areas increase the risk to the participant's professional role (RH 8)
- Lack of performance management increases confidence (RH 10)

What the data appeared to show is that staff are concerned that professionally they do right by people. This may be more pressured because some decisions can present life changing or life threatening risks. The staff may also feel an added sense of needing to do right because the people that they work with have often suffered abuse or experienced negligent practice or prejudice.

Another part to the professional risk is the effect on staff. All participants were aware of the potential professional (e.g. being sacked or 'struck off') or legal (challenges though court) consequences of decision making. As the decision is based on 'reasonable belief' there are no absolutes, so the staff need to justify how they arrived at a decision. Even without litigation, a poor assessment could be challenged by colleagues or other professionals. This could expose the staff to being viewed as incompetent or negligent, and impact on their own feelings about their professional standing.

3.4.2 Core category 2

Using the MCA can lead to **"emotional or psychological risks**". This was discovered from testing and following up on a number of hypotheses:

- There are emotional processes involved in the use of the MCA (PH 1)
- Applying the MCA involves psychological risk taking (PH 3)
- Understanding contextual issues about the person affects the use of the MCA (PH 9)

- The significance of the decision to be made can increase the ease of assessment (RH 6)
- Decisional grey areas affect the participant's psychological processes (RH 9)

The data suggest that the staff have some level of emotional attachment in their care of PWLD. The context of abuse and prejudice brings about protective feelings. The significance of the decision pulls on them to 'will' for the best outcome. Unwise decisions, in particular, create uncomfortable feelings as it is difficult to stand back and watch as people they care (professionally and personally) for, take risks with their health, safety or wellbeing. Ben and Harry call this paternalism, which appears to be an accurate way to describe common feelings expressed by staff.

3.4.3 Core Category 3

The staff used "**strategies to mediate risks"** that applying the MCA and subsequent decision making may present.

The potential for any kind of risks require that staff develop strategies to make their practice safer for all concerned. The risks are moderated by a number of strategies as highlighted in the testing of the following hypotheses:

- People develop strategies to reduce the risk to themselves when applying the MCA (PH 4)
- Peer support is important to staff using the MCA (PH 10)
- Peer support improves confidence (RH 2)
- Decisional grey areas increase the risk to the participant's professional role (RH 8)
- Decisional grey areas affect the participant's psychological processes (RH 9)
- Lack of performance management increases confidence (RH 10)

The common factor to safe practice is peer support. It helps staff manage the professional risks by getting a clear sense of the process they need to use for assessment or decision making, and psychologically to assist with feelings about the outcome (be it validation of the process/decision or a sharing of feelings about the case).

Peer support is also good for sharing responsibility. That, along with teamwork (working within a MDT), provides clarification and permits everyone to 'sing from the same hymn sheet', justifying that what staff have done would have been done by others on the team too. This 'safety in numbers' diffuses the burden of responsibility and is important for providing reassurance to staff that the sense they make of a situation is right – and furthermore that they are doing a good job.

> *"Well everybody else is doing the same so it just gives you that confidence that we are all singing from the same hymn sheet and we're doing the same thing."* –Fay, 203-204

Staff also use supervision to 'check out' the process they have used and any decisions they have arrived at. This may further share the responsibility, as the information has been passed along to their senior. It is unclear what this relationship actually does beyond this, but it is possible that there is an assumption from the staff that supervision would guide or help correct decision making.

Another safety strategy that the staff use is to refer to documentation. They rely on available literature and protocols to guide them which gives them some standard to which they can justify their actions if they ever need to. Another safety strategy they have in relation to documentation is the need to document their own actions – this makes their processing transparent to others if it were to come under scrutiny and aids justifying any decisions made.

A further safety strategy is somewhat controversial (and will be explored further in the discussion). At times, staff make ‘safe’ decisions or have a ‘safe’ strategic approach to assessment. This means that when grey areas or risks are posed, their practice is such that best interest decisions are favoured. It is not clear if they have neglected to assess, or indeed assessed then formally stated ‘no capacity’. Decisions made may not be ‘wrong’ decisions. They may be reasonably justifiable within the principles of the MCA where an argument can be made either way, especially in grey areas. But there is a suggestion in the data that best interest decisions are safer than the risks that otherwise exist; that those best interest decisions not only lower the risk to the service user by preventing them from making a risky or bad decision, but also help the staff reduce emotional or professional risk to themselves. It is possible that a best interest decision feels like a safe ‘win-win’ situation, as long as the decision is justifiable to the team.

This is perhaps the key point of the participant’s behaviour: justifiability. Whether the risks are professional or personal, the procedures of all staff are those which seek to justify their actions. Peer support does this through sharing process and outcome issues; teamwork shares responsibility for decision making, seeking documentary clarification and ensuring all actions are documented also provide room for justification and defensibility, and safety strategies such as ensuring riskier situations are handled in a way that is justifiable seems an important part of the process of using the MCA.

Chapter 4

4.1 Discussion

This chapter will summarise and appraise the theoretical framework, and then the core conceptual categories will be reviewed within the context of the existing research literature and in relation to the research questions. Researcher reflexivity, limitations and clinical implications of the study are also discussed here, along with recommendations for future research.

4.1.1 Review of the findings

The aim of this study was to develop a theory about how staff working with PWLD make sense of and use the MCA in routine clinical practice, and to examine factors that might influence the use of the Act. The MCA has been welcomed by staff, and embraced as a framework with which to champion the rights of service users, safeguarding them against risks and promoting their needs and wellbeing in wider health and social care settings. The task of using the MCA involves a number of steps, from deciding that it needs to be used; providing information and support to the service user; gathering evidence about capacity; and the subsequent decision making about the status of capacity or determination of best interests. The narratives of the participants led to the development of a theoretical framework (figure 3) which found that there are risks associated with using the MCA. A closer examination of these risks led to two core conceptual categories – professional risk and emotional risk. A third core conceptual category described how these risks appear to be mediated by the use of safety strategies. The underlying story of these processes is that staff are keen to ensure that their actions are justifiable against the backdrop of the professional and personal risks they may experience.

Professional Risk – this core conceptual category was experienced by all participants. To some, their awareness of the legislative process (in particular the

concern that decisions could be legally challenged) appeared to be a burden. Whilst none of the participants had experienced such challenges to their work, they reflected that serious professional consequences were a possibility; that potential scrutiny by other professionals was anxiety provoking and that ensuring the rights of the service user may sometimes involve the staff challenging other health care professionals (of perhaps senior level). Subjectivity, experiencing 'grey areas' and the lack of absolutes about decision making may lead to staff being concerned that they could be challenged by colleagues, senior health professionals or even the service user's family about what they have done to arrive at a decision. Any challenges to decision making may delay the process or result in compromised outcomes for the service user (especially if the decision to be made is related to a health issue which is managed in general health services). The professional risk, therefore, is one in which the staff fear being considered neglectful or incompetent in their role.

Emotional Risk – this core conceptual category was also experienced by all participants. Their role had taken each of them to a place of emotional concern for their charge, be it concern that unwise decisions confer other risks, considering how to prevent trauma, harm, or fighting prejudice. Owning paternalistic feelings appeared to come naturally to this group. The possibility of the service user making an unwise decision in particular was a reality they had to deal with. To the staff, caring for PWLD is more than an occupation, and despite legislation to protect the autonomy of PWLD, the desire to protect against unwise decisions was a powerful motivation.

Safety strategies – This core conceptual category explained how staff managed the risks associated with using the MCA. There was some variation amongst the group. However, strategies did not load onto any particular type of characteristic hence the heading being about strategies existing rather than particulars of person and circumstance. One strategy that existed for all participants was peer support. This not

only assisted with working out what to do, but also in justifying both the process (working out how to go about supporting the service user and gathering evidence) and outcome (managing the effects of the decision). 'Singing from the same hymn sheet' and being aligned with peers seemed to promote reassurance, cohesion and acceptance that what was being done was being done properly. The value of teamwork was also important. However, this was in relation to MDT working which is formal and structured (and also consists of non-peer health professionals perhaps with competing agendas). Despite the risk of being challenged or challenging others, the MDT was consistently identified as a place of safety – responsibility was shared, and decisions were justified through the team. Similarly, documenting work was another source of safety. The staff felt that as long as they could show due process, with clear documentation about what they did and how they arrived at that decision, then they were less likely to be vulnerable when challenged by others.

A more controversial strategy used by some of the staff at times of risk (grey areas in particular) was to weigh up the decision, pre-empt risks to the service user by deeming the service user to not have capacity, therefore recommending a best interest decision. Most staff had a sense of anticipatory/preparatory understanding of the service user's presentation and the significance of what the decision could mean to the service user before applying the MCA. Other staff however appeared to have developed a rubric about decision making, suggesting that they only used the MCA 'formally' or in conditions of 'no capacity' to support a best interest decision. Given the existence of grey areas, this is a powerful safety strategy, which not only promotes professional and emotional safety for the staff, but also creates a 'safe' decision for the service user. The use of best interest decisions over unwise decisions at times of grey areas is discussed in detail later in this chapter. Being able to defend the process and decisions in documents, meetings or amongst peers was a key factor to all participants; hence justifiability was a means of ultimate safety.

These three core conceptual categories address the two research questions in appearing to influence the application of the MCA and affect how staff make sense of and use the MCA. The existence of professional and emotional risks will be discussed in relation to existing literature first to set the context of the theory, and then the strategies used to mediate the risk will be explored.

4.1.1 'Professional Risk'

When considering risk issues, it is important to state the factors that are important components to the risk (Carson & Bain, 2008). For this study, key factors to consider are: issues about the MCA that may lead to risk; factors around the decision or associated implications that present a professional risk; and issues about the professional role that present a risk.

The MCA presents some issues that may contribute to risk, these include a lack of criteria to support judgements of capacity (Oldreive & Waight, 2011), subjectivity bias, particularly if there is a close relationship between those assessing and making decisions and the service user, and possible competing imperatives affecting assessments or fluctuations in capacity (Manthorpe, Rapaport & Stanley, 2009; Grove & Meehl, 1996). The acknowledgement of subjectivity is provided in the MCA itself (Department of Constitutional Affairs, 2007) – the evidence required for assessment and decision making only needs to be made upon with "reasonable belief", not, as in criminal law, beyond reasonable doubt. Subjectivity opens up a quest for evidence. Staff may not know just how much evidence constitutes enough, which in turn may leave them feeling that their position is unconvincing in relation to justifying their decision. The fact that the MCA can be construed as a safety net, granting 'immunity from legal action' for those making decisions (McDonald, 2010) appears poorly appreciated by the staff in this study. It is possible that an organisational 'blame culture' exists, instilled through corporate induction or training

in the MCA. Some staff had training provided by legal services who gave examples of problems with decision making that resulted in legal action. This may create a burden of responsibility upon staff (Carson & Bain, 2008) as organisations seek to protect themselves from legal action. This burden appears to exist regardless of stage in the process; assessment (gathering evidence) or decision making, or deciding how to proceed with best interests. Yet amongst the participants in this study these concepts were thought of interchangeably as a risk (i.e. there are risks in processing the assessment and risks involved in decision making). This may be due to staff expecting that their assessment comes under scrutiny (i.e. a risk to their professional standing) as much as a risk about the decision itself. The structure of the MCA does provide a framework that felt safe to some staff:

> *"I find it a very safe framework to work within."* – Anna, 125

Nevertheless, the issue remains that absolute right or wrong decisions are rarely obtainable when using the MCA and this may contribute to a feeling of uncertainty. Thus, healthcare staff may have concerns not only about how poor decision making may affect the service user, but could also be considering implications to themselves or possibly by extension, their employer. These issues may therefore add to the theory that there are professional risks which contribute to how staff make sense of and use the MCA in routine practice.

4.1.2 'Emotional risk'

As with the previous section, the discussion about emotional risk will consider factors around the MCA; implications for staff personally that present an emotional risk; and to them in their professional role.

The five principles of assessment of capacity were set to ensure that they were not too restrictive and could account for a great range of decisions, from everyday

decisions to life changing ones. (Brown, 2011; Brown & Lloyd, 2012). However, not every decision facing an individual with a LD is put to a test of capacity. This could mean that seemingly trivial or small decisions are more likely to be viewed as the individual having capacity at times of no dispute or implied consent (Ferguson, 2010). The staff in this study were aware of that too; not all decisions in a person's life were approached using the MCA, but it was the *significance* of the decision that triggered doubts about capacity, and for the MCA to be used, just as Willner et al (2011) suggested (section 1.6). Given that significance of the decision was important, this may raise the likelihood that staff experience "anticipated emotions" (Loewenstien, Weber, Hsee & Welch, 2001) which may mean that applying the MCA may create a concern in staff about the consequences of decision making leading to harm. This may be in the form of harm to the service user, especially with traumatic or life changing decisions, or harm to the staff in the form of increased anxiety, or perhaps guilt or esteem about their role. Research on the understanding of social cognitive processes explored the role of affect in decision making (Clore, Schwarz & Conway, 1994; Loewenstein, et al 2001; Slovic, Finucane, Peters & MacGregor, 2004). Clore et al (1994) reported that people use affect as information, making social decisions based on like or dislike. Feelings that arise during decision making directly influence the decision as the individual appraises the possible consequences to that decision through their own affect status. Loewenstien et al (2001) developed this further and suggested at times of uncertainty it is the *possibility* of risk rather than the *probability* of risk that drives affect. This can mean that there is disproportionate weight carried for even small probabilities of risk. Slovic et al (2004) suggested that affect helps a person mark out positive or negative aspect of a situation automatically, termed "the affect heuristic." This may not be rational but is based on a primal 'intuition' driven by experience. It is possible that staff in this study perceive risks to service users or themselves based on their experience or understanding about the neglect or abuse service users may have suffered. At times of uncertainty (grey areas) in particular,

staff may be experiencing risk as a feeling. Anticipated emotions generate a vision of what the outcome or consequences could be. This might impact on the decision making process, thus judgements may be made based on fearing negative emotional consequences such as anxiety, worry, or concern for the service user or the staff.

Research by Kahneman and colleages (Kahneman, 2012) identified that when people make decisions, they use two different methods. 'System 1' is an intuitive way, which is experiential and how individuals process basic actions. It involves intentions, associations and affect. The second method, 'System 2' is reflective and more determined, requiring effort. In substitute decision making on behalf of others, the reflective method would ensure that all factors are considered to balance the decision. Kahneman (2012) argues however, that it is very difficult to escape intuitive thinking; System 1 provides context for decision making, which can involve biases of associations and affect – which means that decision making is rarely wholly objective.

Biases can also have an "anchoring effect" (Kahneman, 2012, p. 119). Some factors can be more influential than others; and inescapably so. For this study, emotional and professional risk (and by extension, corporate risk) may have been an anchor which may have prevented decision making being truly objective. Hence, service users may be more likely to be categorised as having 'no capacity' in order to avoid risks of harm associated with decisions. Galinsky and Mussweiler (2001) suggest negotiating anchor biases by instructing those involved in decision making to think of counter arguments to the anchor, thus focusing the individual back to System 2 and restoring some objectivity.

Another consideration of the emotional risk may be linked to how staff perceive themselves in their role. The staff in this study have taken up the mantle of being professional helpers, and in particular working for the good of PWLD. All participants

chose this career path as their specialism. The narratives revealed their enjoyment in helping people achieve their potential in ways akin to Seedhouse's (1998) model of health care, being that which removes obstacles or managing challenges to human potential. This involves human interaction, a role in which there is a social exchange. To Seedhouse (1998), the ethics of managing this role is on a continuum of 'immoral to moral' to the end that working for healthcare is a 'moral endeavour'. What the individual *does* is based on a range of choices. The choices should explicitly benefit the service user, but health workers make choices based on a variety of motivations, including the size of other obstacles that may have to be considered (such as time, resources, attitude of others, systemic factors). This is not to suggest that immoral practice is common, but the ethical driver for how one works will be tempered by factors within the healthcare professional and the system within which they work. Thus it could be expected that a health worker will understand that there are failings in the 'system', and aspects of 'care' that are not provided to an optimal standard. Yet some will choose to ignore those issues, not rise to challenging the system because the problem seems 'too big' or rather the consequences to the self are potentially damaging, professionally or personally (Seedhouse 1998). Similarly, Lachman (2010) states that nursing and healthcare work involve 'moral courage', which means that 'the right thing to do' may involve risk taking to some degree; striving to maintain clinical practice for the good of the service user may be compromised by competing agendas. This may have a personal effect on the staff especially if they are thwarted or frustrated in the care, possibly impacting on the individual's sense of self, confidence, feelings of competence or develop feelings of fear, anger or shame. In order to take courageous steps, staff need to feel the fear and act regardless of risk (Lachman, 2010). In this study, all participants demonstrated the need to champion the rights of PWLD, and some showed strong moral courage, e.g. Anna, a nurse who, when faced with a GP who was not following the MCA, challenged his work and directed him to educational materials. A second example is Ella, who was frustrated

by prejudiced healthcare practices and so used the MCA to ensure that the service user's rights were upheld. One strategy that helps to manage moral courage is to identify supportive resources available (Lachman, 2010). This is what the participants of this study do. As will be discussed in the next section, peer support and supervision are common strategies that assist with reducing the risks associated with using the MCA.

4.1.3 'Strategies'

Analysis of the narratives showed that staff are involved in a range of strategies which help to mediate against the professional or emotional risks and make their practice safe. The most common of these was peer support. This served a number of functions including being a shared knowledge resource, a place for orientating and coordinating the processes needed to use the MCA, and a way of sharing and diffusing feelings about, and responsibility for, the outcome. This finding is similar to that of Cleary, Horsfall, O'Hara-Arron and Hunt (2012) who found that registered nurses valued peer support as means of de-briefing about work they found to be particularly difficult, but also the opportunity it afforded for reflective practice, advice, encouragement and friendship.

Cranley, Doran, Taurangeau, Krushniruk and Nagal (2011) reported that clinical uncertainty raised emotionally uncomfortable feelings, and that "getting everyone on the same page" (p155) was a common strategy used to manage and reduce uncertainty. Muir-Cochrane, Gerace, Mosel, O'Kane, Barkway, Curran and Oster (2011) also found that nurses needed "to be on the same page" (p731) to assess and manage risk. Collaboration with team members of differing roles and professions, along with verbal and written communications, were key to ensuring that risk to care was managed responsibly. Like the nurses in Cranley et al's (2011) and Muir-Cochrane et al's (2011) research, participants in this study spoke about 'singing from

the same hymn sheet.' Peer support may serve the function of aligning people, creating a safe staff base where approaches to using the MCA are similar. This appeared to be an important safety strategy not just reserved for formal meetings such as the MDT, but also in documentation and other forms of communication. This may serve added functions of promoting collaboration and teamwork and providing equitable care in the face of diverse needs, all of which are required in order to work ethically in healthcare (Melia, 2001). Kahneman, (2012) suggests however, that consensus or group decision making can produce more errors than independent decision making. This is because one group member invariably influences another. Losing the independence factor increases the likelihood of inaccuracy. Kahneman (2012) explains when people are asked to estimate how many coins are in a transparent jar, private responses produce answers closer to the mean than when individuals are allowed to answer in front of others. People are less likely to go with their own original thoughts, and tailor their answer in line with those around them. Kahneman (2012) calls this the correlated error.

Correlated error should be considered in the experiences of staff in this study. In an environment lacking checks and balances of performance management, or standardised training, consensus opinions may be occurring on many levels; during peer support, and also MDT or best interest meetings. How such meetings are run or decisions made is not known, and can only be speculated upon. It is possible that there is a 'group-think' mindset which may be risk averse (i.e. influenced in a way that member by member the attention is drawn to the risks).

Managing uncertainty could lead to the use of safety strategies which may appear at risk of compromising human rights. In this study, it is understood that Cath and perhaps Ella and Iris have an understanding of the MCA which allows them to make

clear decisions about using it i.e. there are few grey areas, most assessments end up with ‘no capacity’ statements and therefore best interests actions are applied. In addition to this, other staff, including Harry and Kerry show a preference for managing grey areas through determination of ‘no capacity’ and therefore best interests. This was also found by Cranley et al (2011) who stated that uncertainty was managed by putting the service user first, ensuring a best interest decision was a priority. This however, is Canadian research, and the participants were not subject to the statutory requirements of the MCA. Nevertheless, the strategy discussed is similar to that found in this study; decisional grey areas were managed by collaboration with the MDT and peer support all of which sought to justify decisions (Cranley et al, 2011). This safety mechanism has also been identified by Stewart, Bartlett and Harwood (2005) and Walters (2009), who acknowledge that, despite the moral endeavour, the clinician’s agenda may compromise autonomy through choosing to make safe decisions to prevent harm to the service user or to reduce the possibility of legal, professional or emotional consequences. The difficulty with this strategy is that there is a subtext which may be perceived by observers that the removal of the right to autonomy is acceptable in order to preserve clinical or professional safety. This goes against the very principles of autonomy and suggests that a paternalistic model of healthcare provision still exists.

Some studies have examined the processes of decision making in clinical practice and the effects on autonomy. Thornton (2011) suggested that deciding between lack of capacity and an unwise decision is about the outcome, and that this has to happen because there are too many unknown issues within the processes of decision making. The process of decision making requires staff knowing about the mental mechanisms that underpin real determinism. This is a flawed approach because generic labels are applied to the concepts of ‘understanding’ and ‘weighing up’. Effectively this means there will be variance across any group of people having these

terms applied to their thinking, as the latent nature of the mental mechanism means that staff can never be certain about two key aspects of the assessment process (understanding the information and to weigh up that information relevant to the decision), (Department of Constitutional Affairs, 2007). Best interest decisions may then be led by concerns about the outcome rather than the process of determining capacity. In a study looking at refusal of medical treatment by adults, Bingham (2012) reported that staff apply 'consequentialist theory' to their practice where they override a service user's decision through justifying that different strategies makes for a better clinical outcome. Such paternalism in clinical practice can still hold moral beneficence as a fundamental part of the care even if the strategy causes a conflict with autonomy. Healthcare staff are obliged to put autonomy first, but at times this may mean them colluding with a risk of harm occurring and it is managing this tension that leads to safe decision making (Bingham, 2012). In a study about nursing people with asthma, Upton, Fletcher, Madoc-Sutton, Sheikh, Caress and Walker (2011) found that although nurses said they shared decision making with the service user, in practice they were more paternalistic – offering choice, but limiting information. When this was explored, nurses believed that good patient outcomes were the most important aspect of their role. This 'nurse knows best' strategy is manifest under a guise of supporting autonomy in decision making, but is subtly very powerful. Choice is limited and autonomy is compromised but the benefit is likely to be the improved health or wellbeing of the individual. With respect to PWLD, Fyson and Cromby (2012) argued that an era of choice has led to service development in which "permissive rights gain primacy over protective rights" (p3), and whilst it is imperative that human rights are upheld, there are times when the realism of a 'choice' is likely to bring about negative consequences. Choice may be part of a path of good intentions which is not always paved with gold; it is seen to be a positive aspect of care, but only if the choice is meaningful to the service user. Despite reasonable arguments about choice and risk, the Nursing and Midwifery Council

(NMC) state that guidance from courts should be sought at times of dispute about capacity or best interests and that even at times of serious risk of harm, if the service user has capacity, their decision should be respected and that other agendas such as the personal feelings of staff should not be permitted to influence decision making (NMC,http://www.nmc-uk.org/Nurses-and-midwives/Regulation-in-practice/Regulation-in-Practice-Topics/consent/ retrieved 28th November, 2012)

The safety strategy of looking to best interest decisions for managing grey areas needs to be understood, therefore, in the context of a moral endeavour. Staff in this study aim to help the individual fulfil their own potential by removing obstacles, but that also includes removing harm, and they may be aided by having an objective idea about what a 'good' outcome for the service user may look like. The cumulative effect of bearing risks (given those mentioned in the previous sections) to their professional status and emotional well being, may mean that managing the use of the MCA needs to be scaffolded by other structures such as formal team meetings, clinical supervision and use of the MDT. These strategies, along with producing clear documentary evidence, help diffuse risk to individual staff, create safe outcomes for service users, but ultimately result in enabling justification of decisions should there be any problems encountered, or challenges to the decision.

With respect to the research question regarding which factors influence the use of the MCA, the findings of this study therefore show that safety plays a role. The participants acknowledge that they do not use the MCA for every decision in a service user's life, but the significance of the decision that has to be made triggers the need to balance the potential outcome against the need to safeguard against harm and prejudice. Thus, context and significance of the decision influence the use of the MCA.

4.1.4 'The role of experience'

An important element to understanding what facilitates staff in their use of the MCA was consideration of experience, confidence and competence. Whilst these issues did not map onto the theoretical model in any clear way, they were a continued focus of the context to the study and have provided some insights to what may be important to staff development.

The analysis showed that experience improved confidence, and that this experience was not based on length of time (years) working with PWLD, but rather the number of assessments (i.e. practical use of the MCA). It was demonstrated that self-defined competency was less due to gaining experience (how many times the staff used the MCA), but more that developing a sense of security or self-assuredness was important. Interestingly, training did not appear to be a factor in their understanding and use of the MCA, but what the staff did find important for this was the role of peer support. This is in line with established theories about education in clinical practice – that learning is not just cascaded down hierarchically, but is richly developed through a "network of peer relationships", (Christiansen & Bell, 2010, p. 803)

This may be better explained through a model of experiential learning such as that of Kolb (1984), who proposed that there are four key stages of learning that occur after the initial use of a skill or task; reflection, discussion, analysis and evaluation (Gibbs & Priest, 2009). The participants in this study appeared to be able to use the four stages during peer support in which they shared thoughts, discussed cases and concerns, analysis of what they did and ought to do, and evaluated outcomes. Staff reported that peer support facilitated all of these stages, even if they were not sequential. It is possible that peer support is part of the experiential learning cycle, which in turn helps with managing any adaptations that may be needed to cope with the risks and demands of using the MCA in meeting the needs of a heterogeneous

clinical population. Quality peer support has been shown to have a direct impact on learning (Chesser-Smyth, 2005; Gilmore, Kopeikin & Douche, 2006; Goldsmith, Stewart & Ferguson, 2006). Iwasiw and Goldenberg (1993) found that peer support benefitted both the role of peer supervisors and supervisees, conferring increased knowledge, independent learning and understanding effective teaching methods across the clinical team. Gibbs and Priest (2009) reflected that peer support may be rewarding, and that positive feedback is likely to spur on continuing gains in learning and skill development. Other benefits include a sense of acceptance which helps staff manage their work, support at difficult times and a shared understanding about experiences. Importantly, peer support facilitates more concrete aspects of skill development particularly when conducting assessments or using physical interventions (Christiansen & Bell, 2010).

The findings of this study demonstrated that peer support was at times a shared knowledge base and a safe place to explore and learn ready to implement what had been learned. It may be important to consider the development of peer learning as a formal educational and support model for clinical practice. This will be explored further in the next section.

4.2 Clinical implications

This study has given rise to some clinical implications that should be considered, especially with respect to monitoring clinical practice and managing the effect of clinical practice on staff.

This study raises questions about staff support systems and what might be needed to help manage difficult feelings that develop through their clinical role. The analysis suggested that staff experience a range of risks, both professional and emotional

that pertain to themselves and service users. Whilst some staff did talk about using supervision, assumptions cannot be made about the structure, function or availability. Given that peer support is so valuable an action learning model (McGill & Beatty, 2001) would perhaps be a good way of setting support, learning and problems solving around these risks and around the practical use and implementation of the MCA.

Furthermore, some participants spoke about direct experiences or of knowing about abuse and prejudice, at times with grave consequences which appeared to have a marked effect on them. This makes it important that regular clinical supervision is available for all to ensure good mental health and emotional wellbeing of staff and reduce the likelihood of burnout. It may be prudent for clinical supervision to monitor boundary issues. Some staff have long term professional relationships with service users, becoming involved at critical periods of their life, and getting to know home and family circumstances. The risk is, therefore, that it becomes difficult to remain completely objective about some of the decisions that need to be made. Clinical supervision could provide this function.

Reflecting on difficulties with decision making, Kahneman (2012) states that he is not optimistic that people can really be objective (System 2 thinking) without ‘intuitive’ (System 1) thinking having some influence. Klein (2007) suggests that correlated errors and anchoring bias can be reduced through using a ‘premortem’. Here, all risks are identified at the beginning of decision making, and thinking is structured using tools. In understanding that decisions can bring about uncertainty, the use of tools such as Seedhouse's (1998) ethical grid may support staff in their decision making. This will ensure that decisions are made with best interests of the service user rather than staff or the wider service, especially when the outcome presents

risks. In the absence of performance management, the ethical grid, in conjunction perhaps with clinical supervision and the peer learning model may safeguard against paternalistic practices.

Practice guidelines already exist (Department of Constitutional Affairs, 2007) and those produced by the BPS (Joyce, 2008) have a good focus on the types of decisions to be made and how to go about them. These guidelines, however, assume objectivity in assessment and decision making. Good practice guidelines perhaps should be brought up to date factoring in uncertainty and the difficulties that may occur and how to overcome them given the relational way of working.

It may be useful to disseminate the findings of this study within LD services to raise awareness of how the MCA has been used and help them develop reflective practice to address this issue.

4.3 Further research

The study may contribute to the existing literature about the use of the MCA in the following ways. Firstly, studies have shown that there are gaps in the knowledge of staff that may be expected to use the MCA (Evans et al, 2007; Fisher-Jeffes et al, 2007; Sawhney et al, 2009). This research supports the development of specific approaches to knowledge and education about the MCA. It is perhaps not about learning the statutory principles alone but instead about what is needed to use it - more akin to clinical skill development, which may be better facilitated through peer learning rather than formal/corporate/mandatory training.

Secondly, research by Fisher-Jeffes et al (2007) and Ferguson (2010) raised concerns that substitute decision making was not standardised in its application, and

that issues other than capacity were considered in decision making. It could be assumed that paternalism is an arrogant clinical position which poses a threat to the rights of the individual. The findings of this study perhaps open up the debate on the difficulty of applying substitute decisions in suggesting that beneficence and the moral endeavour can still be achieved in the face of paternalism, and that perhaps what matters more is the context, and whether the choice the individual has is meaningful (Fyson & Cromby, 2012). This is not to say that a paternalistic model of care should be accepted, but it should be understood and monitored.

The nature of a GT study is such that it sets out to examine the experiences of people and draw out theories about what is happening in terms of social processes. The core conceptual categories could be the focus of further research. There is a wealth of research literature about actuarial risk assessment and management, but the focus on managing uncertainty at an interpersonal level and the risk it brings to staff's understanding of their professional and personal standing is less well understood. The findings of this study suggest that even when responsibility for final decision making does not rest with the assessor, there is a residual concern for staff about the impact of the decision to the service user, and to themselves. Examining use of the MCA by different grades of staff, with differing responsibilities (such as a psychiatrist or general practitioner) may uncover whether this is specific to some occupations and not others, and why this might be.

Further research could more closely examine the strategies that staff use to maintain safe practice. It was not clear from this study which staff engaged in what type of safety strategy and under what circumstances in particular. This may develop clinical practice by monitoring and guarding against safety strategies becoming at best unhelpful and at worst unlawful. It would also be interesting to find out more about who benefits most from safety strategies - staff or service users. It would be important to gain a clearer understanding about the cost of such practices to human

rights, and both the short and long term outcomes of decision making to the health and wellbeing of service users - opening up the debate on protective versus permissive healthcare practices.

The findings of this study suggest that peer support has greater impact than merely occupational cohesion. It also is a place for education and support for clinical practice. This occurred without any formal model of peer learning being available at this service. Further research therefore, could evaluate the usefulness of formal models of peer learning applied as a method which supports formal learning in clinical practice, especially with respect to the use of complex policies and assessments and the associated risks.

4.4 Study Limitations

The research set out to involve up to 15 participants. Eleven people participated and by the final two no new or alternative data emerged from the interviews. On consultation with the study supervisor (JW) regarding the second phase data it was believed that saturation was achieved. Whilst the data did fulfil the research aims, there are limitations to be considered.

The study recruited from one service, which could mean that the narratives reflect experiences which are unique to that service. This could have been countered by inviting staff from other LD services to participate, which may then have produced variation in the data. Recruiting from one service may have impacted too on the purposive sampling method, which may have suffered somewhat because of this. The service appeared to have a bounty of staff who had worked in LD services (for this Trust) for decades. It was difficult to recruit participants with differing clinical experiences or with fewer years working with PWLD. Similarly, there were more nursing staff recruited than other occupations, which placed a risk that the

experience of the nursing staff could dominate the storyline. However, it did appear that the non-nursing staff had similar experiences.

A further issue concerns the data itself. All participants were keen volunteers who committed to becoming involved in the study after hearing a presentation about the proposal from the researcher. Given the complexities of the MCA, their motivations for wanting to participate must be considered. It may be that they have altruistic tendencies, however, equally it is possible that they had their own agenda. The staff's clinical time is precious, but they generously gave an hour to participate. It is left to wonder if they wanted to communicate something about the MCA. Certainly Anna, Cath, Fay and Kerry appeared up to date with knowledge of policies and procedures. This may have affected the data collected; perhaps the participants considered the research to be a scrutiny of their work, and so may have been careful to demonstrate what they know, and how good they are at their role, rather than admit to gaps in their understanding. This is an inherent problem with self report (Edwards, 1990). Similarly, this will perhaps impact on the view of competent clinical practice; the staff were unlikely to report that their own conduct was less than professional even if it was in the context of them having difficulty understanding the MCA. Thus the picture of the compassionate champions who are relatively skilled at using the MCA must be viewed with caution.

Another issue is the possible vagueness with which the term 'use of the MCA' was expressed to the participants. It appears that staff have multiple decision making roles in their use of the MCA, from deciding whether to apply it, to assessment issues, decision and determination of best interests. Had there been a focus on specific aspects of applying the MCA such as just the assessment process, then it may have given a better idea about the real process of decision making and risks the staff face.

4.5 Post study reflexivity

In section 2.5 of chapter 2, the researcher's own experiences and assumptions were set out. There were two main issues; that healthcare staff can often be the gatekeepers to healthcare access which can be prejudiced against PWLD, and that discussion about the MCA has often been met with cynicism by a range of healthcare staff.

During the course of the research, the participants demonstrated compassion, and a will to strive for the rights of PWLD to access appropriate services. Importantly, they too had tales about the wider NHS discriminating against PWLD. However, given the storyline about best interest decisions being favoured for reasons of safety, this seemed to rail against championing rights and facilitating autonomy. This was discussed at length during the supervision process to ensure that the data was being observed accurately and was not viewed sceptically as a ruse with which to further control or discriminate against PWLD. The researcher believes that the narratives of the participants are a genuine testament to the moral endeavour of working in healthcare and with PWLD, in that the balance of risks that are presented to the staff and the service user are met in context of the circumstances of the individual.

4.6 Conclusion

This study aimed to examine the use of the MCA in a way that was different to existing research. Other studies have stated that there are gaps in knowledge and application of the MCA, but little was known about how staff use it in routine clinical practice.

In the current study, factors which influence the use of the MCA are often about the significance of the decision to be made, in which staff champion the rights of PWLD or safeguard against risks.

The findings supported a theoretical framework explaining how staff make sense of and use the MCA. Core conceptual categories of experiencing professional and emotional risks were mediated by the core conceptual category of becoming involved in safety strategies which eases the burden of risk. This means that staff are making sense of the MCA in relation to a series of risks, both professional and emotional, pertaining to both themselves and service users. This in turn impacts on how they use the MCA; seeking strategies which feel safe or may otherwise protect them from personal or professional scrutiny. These strategies include peer support, supervision, MDT working, supplementary education, documenting the process, and using the MCA in a way that forces the determination of best interest decisions over unwise decisions in the face of uncertainty. The key issue is justifiability. Ultimate safety is achieved if the actions of the staff can be reasonably justified to others.

There could be implications to using these methods. Firstly, a lack of performance management could lead to 'safe practices' becoming the norm – eventually leading to a dominant paternalistic model of care. Secondly, this could compromise the aim of the MCA which is to help support autonomy. Bringing about best interest decisions at times of 'grey areas' may be justifiable (on a case by case, decision specific basis), but ultimately this strategy is a threat to autonomy in order to gain a safe clinical outcome.

An important finding of this study was about the role of peer support. It was a valuable safety resource which supported the process and the outcome. Peer support was also validating and educational. It appeared to consolidate understanding of experiences across the team in a way that is similar to Kolb's

(1984) experiential learning cycle. This perhaps paves the way for introducing a peer learning model alongside formal education and training which may help develop confident and competent practices from the staff involved.

Further recommendations from the study include using tools such as the ethical grid (Seedhouse, 1998) to guide decision making at times of uncertainty, and also to promote the use of formal, regular clinical supervision to monitor staff wellbeing and any issues that may arise (including attachment to service users) that could pose a challenge to good clinical practice.

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Appendix A

Ethical approval

UNIVERSITY OF LIVERPOOL

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Julie McVey
Year 3 Trainee Clinical Psychologist
31st January 2012

RE: Examining experiences of healthcare staff in using the Mental Capacity Act (2005) when working with people with a learning disability.

Dear Julie

On the understanding that your responses to the Research Committee have been discussed and approved by your supervisors you have been granted Chair's approval for your revised research project, and approval to progress to the next stage of your research.

Good luck with your study.

Yours sincerely

Ian Fletcher

Dr Ian Fletcher (Chair Yr 2 DClin Research Committee)

Dr Julie McVey
Trainee Clinical psychologist
D. Clin Psychol Programme
The University of Liverpool
Division of Clinical Psychology
The Whelan Building
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3rd May 2012

Dear Dr McVey

Formal Letter of Approval

Trust Ref: 2012/15: Examining experiences of healthcare staff in using the Mental Capacity Act (20005) when working with people with a learning disability

Thank you for your research application which was disseminated to the Trust's Research Governance Committee for electronic review.

Comments received were positive and after review by the Committee and the R&D department, I am happy to take Chair's Action to approve the study on behalf of the Committee.

Dr [redacted] confirmed service and [redacted] support on the 2nd May 2012.

Under the new Governance Arrangements for Research Ethics Committees (GafREC) issued by the UK Health Departments, which came into effect on the 1st September 2011, the above study no longer falls within the remit of NHS Research Ethics Committees (REC) and therefore does not require REC review.

Accordingly, please take this letter as confirmation of Trust R&D approval on the basis described in the application form, protocol and supporting documentation as revised.

Please read the attached *'Information for Researchers – Conditions of Research Governance Approval'* leaflet, which details the research governance R&D approval conditions. Please contact the R&D Office should you require any further information. You may need this letter as proof of your approval.

Please note when contacting the R&D office about your study you must always provide the project reference number quoted above.

May I wish you every success with your research.

Yours sincerely

Sponsor: The University of Liverpool
Contact; Lindsay.carter@liverpool.ac.uk

[redacted] NHS Trust is a smoke free NHS Trust and operates a smoke free policy.
Please note that smoking is not permitted on any of our sites including buildings, grounds, and car parks.
Smoking is not permitted at the entrances or exits of buildings and sites.

Appendix B

Information sheet

PARTICIPANT INFORMATION SHEET

Examining experiences of healthcare staff in using the Mental Capacity Act (2005) when working with people with a learning disability

Invitation

You are being invited to take part in research exploring participants' experiences of using the Mental Capacity Act (2005). Before you decide whether to participate, it is important to understand why the research is being conducted and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Do please ask if there is anything that is not clear or if you would like more information. Thank you for reading this document.

What is the purpose of the study?

The Mental Capacity Act (2005) is a complex legislative framework. This study aims to explore how staff working with people with a learning disability makes sense of and use of the Act. The objective is to attempt to gain an understanding of the factors that influence applying the Mental Capacity Act (2005) in clinical practice.

Why have I been chosen?

We are inviting all staff who have used the Mental Capacity Act in their clinical practice over the past six months.

Do I have to take part?

It is up to you to decide whether or not to take part. A decision not to take part will have no consequence to your work.

What will happen next?

If you would like to take part it will involve meeting with the researcher at a time convenient to you to be involved in a one-to-one interview. This will take place in a private room and will last approximately 1 hour (although you may want to talk for less than this, or for longer). The researcher will have a semi-structured interview schedule with some areas of questions. These will focus on what training you may have received, what factors you consider in using the Act, and what influences or hinders you in practice. You will not be asked to discuss individual cases. Interviews will be audio-recorded and then will be later transcribed. Once they have been transcribed, the

recordings will be destroyed and we will not hold any information that can identify you. If you do not wish your interview to be audio-recorded you will not be able to take part in the study.

Risks/Benefits

It is not anticipated that there would be any risks to taking part. However if issues of suspected malpractice were disclosed this would need to be discussed further with the research team and potentially the Trust. Although there may not be any direct benefits for participants taking part, it is anticipated that if we have more understanding of the complexities of using the Mental Capacity Act (2005) it may used to develop appropriate support for healthcare staff in the future.

What if something goes wrong?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Laura Golding on 0151 795 5454 or l.golding@liverpool.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Governance Officer on 0151 794 8290 (ethics@liv.ac.uk). When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researchers involved, and the details of the complaint you wish to make.

What will happen to the results of the study?

The study is being completed as part of the researchers training in Clinical Psychology and the results will be written up in a thesis to be submitted to the university. In addition to this the results will be written up into an article and it is anticipated that this will be published in the future in a peer-reviewed journal. Some extracts of what you say may be included in the write-up, but this data will be anonymous. You will not be identifiable from the results.

What will happen if I want to stop taking part?

If you decide you no longer want to take part in the research, you can withdraw at anytime, without explanation. If you decide you no longer want to take part during the interview, the interview will be stopped and the data up until that point may be used, if you are happy for this to be done. Otherwise you may request that the audio-recording is destroyed and no further use is made of it. If you change your mind after the interview has been conducted and the data has been anonymised, it will still be included in the results, however you can request for the audio-recording to be destroyed if it has not already been anonymised and this will be done.

Confidentiality

Interviews will be conducted in a private room and will be anonymous. However if you disclose something which leads the researcher to be concerned for yours, or others safety then the researcher will need to inform their supervisor. There will be no

identifiable information in any of the interview data and all data will be presented anonymously.

Contacts for further information

For further information about this study please contact: Julie McVey, Trainee Clinical Psychologist (Julie.mcvey@liverpool.ac.uk) on 0151 794 5530. If I am not in the department, you can leave a message with reception I will phone you back.

Appendix C

CONSENT FORM

Title of Research Project:	**Examining experiences of healthcare staff in using the Mental Capacity Act (2005) when working with people with a learning disability.**	Please initial box
Researchers:	**Dr Laura Golding, Dr James Williams, Julie McVey**	
1. I confirm that I have read and have understood the information sheet dated 04/03/12 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily		
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.		
3. I understand that only the individuals named above and an interview transcriber will see the information that I give. I give permission for these individuals to have access to this data.		
4. I agree that the researcher may use direct quotes from my interview responses in the report of the study. I understand that I will not be identifiable from any quotes used.		
5. I agree to my interview being recorded for transcription using a Dictaphone. I understand that the resultant MP3 files will be stored in line with University data storage procedures and will be deleted on completion of the study.		
6. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish, before the analysis of the data commences.		

7. I understand that the relevant data collected during the study, may be looked at by individuals from the University of Liverpool, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data.	
8. I understand that confidentiality will be breached in the event that I or anyone else is believed to be at risk of serious harm.	
9. I understand that disclosures of potential risks to people or clinical practice may be discussed with supervisors of the project and the Trust.	
10. I agree that the researcher may contact me to ask whether I would like to discuss the outcomes of the research.	
11. I agree to take part in the above study	

Participant name Date Signature

Researcher name Date Signature

Contact details of Lead Researcher (Chief Investigator):

Dr. Laura Golding,

Academic Director
D.Clin.Psychol. Programme
The University of Liverpool
Division of Clinical Psychology
The Whelan Building
Brownlow Hill
Liverpool L69 3GB
Tel: 0151 795 5454
l.golding@liverpool.ac.uk

Appendix D

Interview schedules 1 and 2

First interview schedule

Title: Examining experiences of healthcare staff in using the Mental Capacity Act (2005) when working with people with a learning disability.

Always state for the tape -

"Before we start I need to remind you that client confidentiality must be maintained at all times, and that examples that you may provide for illustrative purposes should be given with appropriate care to not speak about potentially identifiable information. Concerns that may arise from the interview that could demonstrate compromised practice will be pursued in line with ethics guidelines for this service.

Is that OK?

Do you have any questions?"

The person

1. Tell me your job title and about your role in this service.
2. Tell me about your occupational background, perhaps prior to coming into this post.
3. Tell me a bit more about your job here, describing what it is you do; what is expected of you in your role and responsibilities.

Knowledge, training and support

4. Could you tell me what you know about the Mental Capacity Act (2005)
5. Could you describe any training you have had about the Mental Capacity Act; (format, who delivered it, how long it took, was knowledge tested – if so how? is it performance managed? or audited? Are there any requirements for mandatory training?)
6. Could you tell me how confident you feel in your knowledge about the MCA? (Explore lack of confidence, what is that about?)
7. Could you tell me about how confident you feel in relation to conducting an assessment? (Explore lack of confidence, what is that about?)

Practical application

Without discussing details of the case, could you be mindful of the last MCA assessment you did to reflect on the following questions:

8. Could you tell me what made you decide that the Mental Capacity Act may be needed? (Perhaps looking for a range of factors here. May prompt "is there anything else?")
9. Tell me how you would go about doing a Mental Capacity Act assessment.
10. What happens next?
11. Is anyone else involved in making this assessment? (if so, tell me more about this; how does it go?)
12. Tell me about any implications a capacity assessment may have? (leave open, the participant may reflect on the client or the service, or them self).
13. Tell me about problems have you encountered whilst conducting an assessment for capacity?
14. Tell me about what helps you manage this part of your job?
15. Could you tell me about what factors help you or help facilitate this part of your job?
16. What important lessons have you learned in your experiences of using the MCA in your job here?
17. Are there any things about training and delivery of assessments of capacity that you would change? (could you tell me more about that – what would that change do?)

Second Interview Schedule

"Before we start I need to remind you that client confidentiality must be maintained at all times, and that examples that may be provided for illustrative purposes should be given with appropriate care to not speak about potentially identifiable information. Concerns that may arise from the interview that potentially demonstrate compromised practice will be pursued in line with ethics guidelines for this service.

Is that OK?

Do you have any questions?"

The person

1. Tell me your job title and about your role in this service.
2. Tell me about your occupational background, perhaps prior to coming into this post.
3. Tell me a bit more about your job here, describing what it is you do; what is expected of you in your role and responsibilities.
4. what does working for health mean to you?

Knowledge, training and support

5. Could you describe any training you have had about the Mental Capacity Act; (format, who delivered it, how long it took, was knowledge tested – if so how? is it performance managed? or audited? Are there any requirements for mandatory training?)
6. Do you know that training your colleagues might have received?
7. Could you tell me how confident you feel in your knowledge about the MCA? (Explore lack of confidence, what is that about?)
8. Could you tell me about how confident you feel in relation to conducting an assessment? (Explore lack of confidence, what is that about?)
9. Tell me about your experience of using the MCA - when you decide to conduct an assessment.
10. Thinking about how competent people feel, what makes you feel competent? What would help you feel more competent?

Practical application

"Whilst being mindful of the obligation to maintain client confidentiality, could you consider perhaps a recent MCA assessment you did and reflect on the following questions:"

11. Could you tell me what made you decide that the Mental Capacity Act may be needed? (need to prompt specifically for client, context, family involvement issues directly if they're not offered)

12. Other staff have suggested that they use the MCA 'informally' and 'formally' with clients. Does this sound familiar to you too? What sense do you make of this in your use of the MCA?
13. Assuming that not all decisions are straight forward, how do you manage the assessment when there are grey areas? (Bear this question in mind whilst they are answering Q9, as it may fit in there or within Q10.)
14. Tell me about any implications a capacity assessment may have? (ask about it in relation to the client or the service, or them self).
15. Could you tell me what factors hinder you when you're doing this part of your job?
16. Could you tell me about what factors help you or help facilitate this part of your job?
17. Are there any things about training and delivery of assessments of capacity that you would change? (could you tell me more about that – what would that change do?)
18. Other participants have spoken quite a bit about peer support, I was wondering why does that help? What does it do for you? (looking for process or outcome).

Appendix E

Examples of memos from journal

→ Fonch & Stg 2.

Feels like a lot of responsibility - but
free resources from MCA help with this
(training, education + support → safety strategy
to help manage feelings). → also not used MCA docs
formally, but has used docs
available on Intranet.

↓

These resources ease the ~~burden~~ burden as
they structure the care plan, involve MDT and
ultimately its not one persons choice, its
a joint choice (diffusion of responsibility)?

↓

She says - not just that, but more the
cumulative knowledge of these "solidifies"
the decision.

Competence is driven by continued experience.
This involves also getting good feedback about how
interventions have worked / helped.
Peer support is used by this person as an outcome
source too; feels competent when peer says she would
have come to same conclusion.

Competency in MCA also driven by experience
ALSO there's back-up - so if things aren't so
good as a result (for the client) then it can be reviewed
to see if there are changes in cap. (and improvements
can be made). THIS IS A SAFETY STRATEGY FOR
MEDIATING AGAINST EMOTIONAL PROCESSES / PSYCHOLOGICAL
RISK

Good. Quote — Capacity is individualised - ? Subjective

14:15 Unwise decisions difficult. - "paternalistic issue"

18:26 LD staff have a lot of responsibility given to them to support others.

New ? ← Judging the levels of understanding of the client including the comprehension of the information that needs to be given to the client is important. So you don't want to limit the clients' chances of having their say because the information has been too difficult to comprehend.

↳ This is a new angle on the assessment.

→ Does anyone else mention (directly or indirectly) the provision of information as a tricky step?

perhaps #1; ?#3; perhaps #4; perhaps #7

→ What does this information say to me?

There needs to be some a) knowledge of the client; b) knowledge about the decision / intervention, c) a matching for optimum info exchange.

What are the risks? - That the client is overlooked and doesn't get their say because they couldn't comprehend or communicate? - When the info is a different way of putting the info could result in the client having choice. (Click to Client). what is

SEE PINK TAB re #3 [illegible]

→ [illegible] in [illegible] + [illegible] BI

The risk to the staff? #8 does say that in a way its easier if they don't have capacity. Best decisions can be made; but what if no one notices or checks?

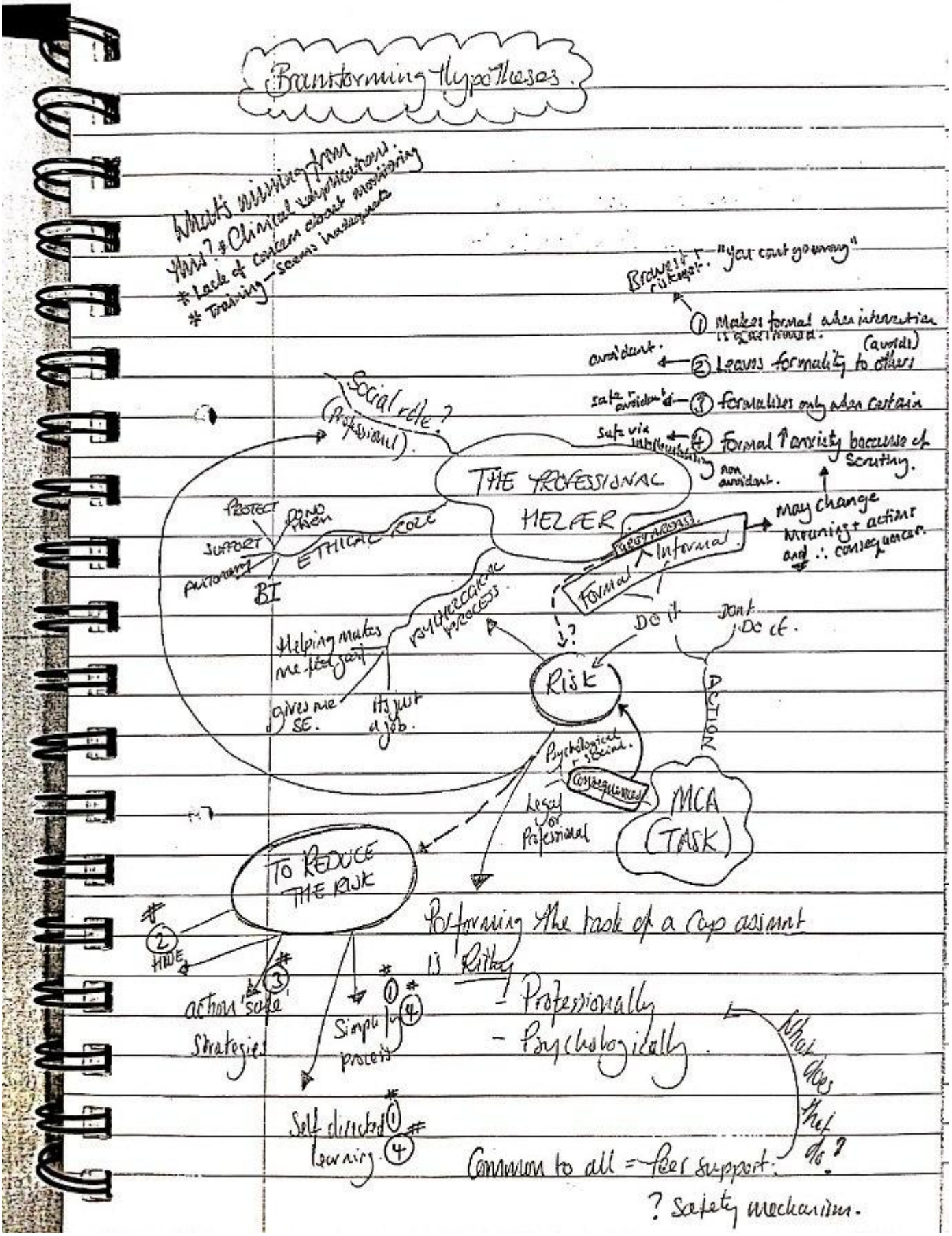
↳ Clients don't have their rights respected at the cost of having BI - in theory would some people argue that this is an all round winner? (even though its not). If no one checks then no one knows, would people say "Well there's no harm done because a BI was made which is great"?

Is the risk that the staff prefer BI because its emotionally and professionally safer; do they err on the side of BI unconsciously almost? At this guy theres a clear endeavour to match info to capacity level to ensure HR isn't breached, but one numbers #2, 3, and 5, (and 7?) playing safe in their use of knowledge about who ~~has~~ has capacity and who lacks?

19:30. Backing it up - justifying - Makes one COMPETENT.

If the client or families don't understand what is being put across then he would feel incompetent

22:00. Statement of rubric. Act is in back of mind all of the time → like #1.


Brainstorming Hypotheses.
What's missing from this? * Clinical implications.
* Lack of concern about monitoring
* Training - seems inadequate
Bravest? risk taker. "you can't go wrong"
① Makes formal alert intervention is questioned. (avoid)
avoidant. ② Leaves formality to others
safe avoidant ③ formalises only when certain
safe via inattentiveness ④ Formal ↑ anxiety because of scrutiny.
non avoidant.
may change meaning + actions and ∴ consequences.
Social role? (Professional).
THE PROFESSIONAL HELPER
PROTECT
DO NO HARM
SUPPORT
AUTONOMY
ETHICAL CODE
BI
Informal
Formal
Helping makes me feel good
gives me SE.
its just a job.
psychological process
Do it
Don't Do it.
Risk
ACTION
Psychological + social.
Consequences
Legal or Professional
MCA (TASK)
TO REDUCE THE RISK
Performing the task of a Cap assment is Risky
- Professionally
- Psychologically.
What does that do?
② HWE
action 'safe' Strategies
③
Simple process
① ④
Self directed learning
① ④
Common to all = Peer support.
? Safety mechanism.

Implications — Client risks → Dr

Professional risks = ↳ Self → wrong decision; does opening up

→ questioning knowledge or competence

Family involvement — risk / implication to PNA Risk

SHE SAYS "I THINK AS LONG AS YOU CAN PROVE

and you have the rationale...

Justify position.

reduces risk

Alpha-numeric list of NVIVO nodes

Alphabetical Node listing
Created in: 14/11/12
Modified in: 14/11/12
Number of Nodes: 140

1 assessing capacity or best interests
2 anxiety or lack of confidence
3 autonomy
4 avoiding trauma
5 barriers to use of the Act
6 best interests
7 beyond control
8 blood pathway
9 challenging others
10 checking
11 client descriptors
12 client understanding
13 communication problems
14 competency
15 concept of the decision (size or effect)
16 confidence
17 consent issues
18 consequences of education
19 consequences of intervention
20 consequences to client
21 considering needs of others
22 contentious issues
23 convoluted practice
24 dangerous or problematic practice
25 decision making
26 deferred responsibility
27 description of the decision to be made
28 developing lines of communication
29 difficulties conceptualising act
30 difficulties in assessment
31 dilemmas and conflicts and competing imperatives
32 discrimination and abuse
33 disempowered
34 diversity
35 documenting
36 education
37 empowerment
38 ends justifying means
39 equality act
40 experience
41 experience of others
42 extra support around MCA

43 factors that affect capacity
44 family involvement
45 feelings about the use of the Act
46 force or against will
47 formal versus informal
48 formulation or hypothesis offered for client problems
49 framework
50 gaps in knowledge and education
51 gathering evidence accurately
52 grey areas
53 hiding behind others
54 how it makes the interviewee think or feel
55 human rights
56 illegal or unlawful practice
57 implications (other)
58 implications of decision
59 implications to service provision
60 information for solicitors
61 information gathering
62 information providing
63 intervention
64 justifying decisions
65 knowledge
66 known to interviewee or not
67 lack of experience
68 least restrictive
69 legal documentation
70 legal or professional consequences
71 legal services solicitors lawyers appointees
72 lengthy process
73 limits to own knowledge
74 lingering paternalism
75 long term decision making
76 MCA safeguarding
77 making decisions quickly
78 maximising
79 medication
80 minimising
81 none committal to opinion
82 normalising
83 opinions on other professionals' understanding
84 other agendas
85 other assessments
86 others challenging interviewee
87 peer support
88 performance management
89 philosophy of Act
90 poly-pharmacy
91 power
92 practice

93 problems with decision making
94 protection
95 querying decision
96 querying other assessments done by others
97 range of intervention options
98 reassurance seeking or providing
99 reassuring the client
100 referral
101 responsibility for assessment
102 responsibility for intervention
103 responsibility for the case or decision
104 risks
105 role in service
106 role uncertainty
107 roles and responsibilities
108 safe hold
109 safe practice
110 safeguarding
111 safety
112 self descriptors
113 self directed learning
114 service users opinion
115 services and policy
116 simplifying the process
117 Stories
118 structured clinical judgement
119 supervision or mentor
120 support at service level
121 support for client
122 support of team
123 supporting families
124 team members
121 teamwork
125 theory about why decisions are not challenged
126 time pressures
127 to use the Act or not
128 training
129 training had
130 training needed
131 transparency
132 triggers to intervention
133 universal standards
134 unwise = query capacity
135 unwise decisions
136 values and principles
137 variation in understanding of the Act
138 what helps
139 what hinders
140 working for health

Appendix G

Initial clustering of codes

Phase one tentative categories developed from clusters of codes.

Codes may appear in more than one category. Some codes became redundant through clustering and will not appear here.

Ideology
Autonomy
Consent issues
Difficulties conceptualising the Act
Human rights
Lingering paternalism
Philosophy of the Act
Universal standards
Values and principles

Knowledge, training and education
Consent issues
Consequences of education
Education
Gaps in knowledge and education
Knowledge
Limits to own knowledge
Self directed learning
Services and policy
Simplifying the process
To use the Act or not
Training
Training had
Training needed
Variation in understanding of the Act

Practice and experience
Assessing capacity or best interests
Anxiety or lack of confidence
Avoiding trauma
Convoluted practice
Developing lines of communication
Difficulties in assessment
Experience
Experience of others
Formal versus informal
Grey areas
Hiding behind others
How it makes the interviewee think or feel
Lack of experience
Least restrictive
Making decisions quickly
None committal to opinion
Practice
Referral

Simplifying the process
Structured clinical judgement
To use the Act or not
Transparency
Triggers to intervention
What helps
What hinders

MCA
Anxiety or lack of confidence
Barriers to the use of the MCA
Best interests
Consent issues
Difficulties conceptualising the Act
Disempowered
Education
Empowerment
Extra support around the MCA
Factors that affect capacity
Feelings about the use of the Act
Framework
Grey areas
Illegal or unlawful practice
Justifying decisions
Least restrictive
Legal or professional consequences
Legal services
MCA safeguarding
Minimising
Practice
Safeguarding
Safety
Services and policy
Unwise decisions
Variation in understanding of the Act

Assessing capacity
Assessing capacity or best interest
Anxiety or lack of confidence
Barriers to the use of the MCA
Best interests
Communication problems
Deferred responsibility
Developing lines of communication
Difficulties in assessment
Ends justifying means
Factors that affect capacity
Formal versus informal
Framework
Gathering evidence accurately
Grey areas
Hiding behind others
Information gathering
Justifying decisions
Known to interviewee or not

Legal or professional consequences
Lingering paternalism
Making decisions quickly
Minimising
Practice
Referral
Responsibility for assessment
Simplifying the process
Structured clinical judgement
Teamwork
Triggers to intervention
Unwise decisions

Monitoring
Checking
Performance management
Reassurance seeking or providing
Supervision or mentor
Support at a service level
Team work

Interventions
Blood pathway
Ends justifying means
Intervention
Medication

Decisions type
Best interests
Concept of the decision (size or effect)
Description of decision
Grey areas
Known to interviewee or not
Medication
Minimising
Normalising
To use the Act or not
Triggers to intervention
Unwise decisions

Decisions challenges
Challenging others
Decision making
Dilemmas, conflicts and competing imperatives
Known to interviewee or not
Others challenging interviewee
Problems with decision making
Querying decision
Querying other assessments done by others
Teamwork
Theory about why decisions are not challenged

Decisions responsibility
Decision making
Dilemmas, conflicts and competing imperatives

Formal versus informal
Grey areas
Hiding behind others
Justifying decisions
Minimising
Others challenging interviewee
Power
Problems with decision making
Querying decision
Referral
Structured clinical judgement
Teamwork
Unwise decisions

Family and contextual issues
Communication problems
Known to interviewee or not
Factors that affect capacity
Family involvement
Formulation or hypothesis offered about client problems
Service user's opinion
Supporting families
To use the Act or not

Implications
Consequences of education
Convoluted practice
Consequences to client
Dilemmas, conflicts and competing imperatives
How it makes the interviewee think or feel
Implications of decision
Implications to service provision
Lengthy process
Making decisions quickly
Other agendas
Responsibility for intervention
Time pressures

Discrimination and abuse
Avoiding trauma
Dangerous or problematic practice
Discrimination and abuse
Force or against will
Illegal or unlawful practice
Power
Safeguarding
Services and policy
Unwise = query capacity

Risk to staff
Anxiety or lack of confidence
Feelings about the use of the Act
Gaps in knowledge and education
Gathering evidence accurately
Hiding behind others

How it makes the interviewee think or feel
Legal or professional consequences
Lingering paternalism
MCA safeguarding
Making decisions quickly
Minimising
Others challenging interviewee
Power
Problems with decision making
Protection
Querying other assessments done by others
Responsibility for case or decision
Simplifying the process
To use the Act or not

Risk to clients
Anxiety or lack of confidence
Client understanding
Communication problems
Consequences to client
Dilemmas, conflicts and competing imperatives
Discrimination and abuse
Ends justifying means
Gathering evidence accurately
Implications of decision
Legal services
Lingering paternalism
MCA safeguarding
Making decisions quickly
Other agendas
Power
Problems with decision making
Protection
Querying other assessments done by others
Risks
Safeguarding
Services and policy
Support for client
To use the Act or not

Safety
Checking
Deferred responsibility
Formal versus informal
Framework
Gathering evidence accurately
Hiding behind others
How it makes the interviewee think or feel
Legal services
Minimising
Normalising
Performance management
Power
Protection
Reassurance seeking or providing

Safety
Responsibility for case or decision
Risks
Safe practice
Safety
Simplifying the process
Structured clinical judgement
Supervision or mentor
Support at a service level
Teamwork
Safety
Triggers to intervention
Universal standards

Confidence
Confidence
Disempowered
Empowerment
Feelings about the use of the Act
Framework
How it makes the interviewee think or feel

Support
Experience of others
Extra support around the MCA
Support
Reassurance seeking or providing
Simplifying the process
Supervision or mentor
Support at a service level
Teamwork
What helps
What hinders

Staff
Role in service
Role uncertainty
Roles and responsibilities
Self-descriptors
Stories

Appendix H

Second wave clustering of codes

1. Emotional processes
assessing capacity or best interests
anxiety or lack of confidence
autonomy
avoiding trauma
challenging others
consequences of intervention
consequences to client
contentious issues
decision making
discrimination and abuse
empowerment
ends justifying means
feelings about the use of the Act
force or against will
framework
grey areas
how it makes the interviewee think or feel
human rights
implications (other)
implications of decision
intervention
known to interviewee or not
legal or professional consequences
limits to knowledge
lingering paternalism
maximising
minimising
normalising
peer support
philosophy of the Act
power
practice
protection
reassurance seeking or providing
reassuring the client
responsibility for assessment
responsibility for intervention
risks
safe practice
safeguarding
safety
unwise decisions
what helps
working for health

2. Psychological risk
assessing capacity or best interests
anxiety or lack of confidence

avoiding trauma
challenging others
checking
competency
confidence
consequences to client
considering the needs of others
contentious issues
decision making
deferred responsibility
difficulties in assessment
disempowered
documenting
empowerment
ends justifying means
feelings about the use of the Act
gathering evidence accurately
grey areas
how it makes the interviewee think or feel
human rights
implications (other)
implications of decision
information for solicitors
intervention
justifying decisions
known to interviewee or not
lack of experience
legal or professional consequences
limits to knowledge
lingering paternalism
maximising
minimising
normalising
others challenging interviewee
peer support
philosophy of the Act
power
practice
protection
reassurance seeking or providing
reassuring the client
responsibility for assessment
responsibility for intervention
risks
safe practice
safeguarding
safety
self directed learning
simplifying the process
structured clinical judgement
supervision or mentor
support of team
transparency
unwise decisions

what helps
working for health

3. Professional risk
assessing capacity or best interests
anxiety or lack of confidence
autonomy
avoiding trauma
barriers to use of the Act
best interests
beyond control
challenging others
checking
client understanding
communication problems
competency
confidence
consent issues
consequences of intervention
considering the needs of others
contentious issues
convoluted practice
decision making
deferred responsibility
developing lines of communication
difficulties in assessment
dilemmas, conflicts and competing imperatives
disempowered
documenting
empowerment
ends justifying means
experience
feelings about the use of the Act
force or against will
formal versus informal
framework
gathering evidence accurately
grey areas
hiding behind others
how it makes the interviewee think or feel
human rights
implications (other)
implications of decision
implications to service provision
information for solicitors
intervention
justifying decisions
known to interviewee or not
lack of experience
least restrictive
legal or professional consequences
Lengthy process
limits to knowledge
lingering paternalism

MCA safeguarding
Making decisions quickly
maximising
minimising
normalising
other agendas
others challenging interviewee
peer support
performance management
philosophy of the Act
power
practice
querying decisions
reassurance seeking or providing
reassuring the client
responsibility for assessment
responsibility for intervention
responsibility for case or decision
risks
roles and responsibilities
safe practice
safeguarding
safety
self directed learning
simplifying the process
structured clinical judgement
supervision or mentor
support of team
time pressures
to use the Act or not
transparency
universal standards
unwise decisions
what helps
what hinders
working for health

4. Peer support
assessing capacity or best interests
anxiety or lack of confidence
challenging others
checking
client understanding
communication problems
competency
confidence
consent issues
consequences of education
consequences of intervention
decision making
difficulties in assessment
dilemmas, conflicts and competing imperatives
experience
experience of others
extra support around MCA

grey areas
implications of decision
knowledge
limits to knowledge
others challenging interviewee
peer support
practice
problems with decision making
querying decisions
reassurance seeking or providing
responsibility for case or decision
supervision or mentor
support of team
team members
teamwork
what helps

5. Training
anxiety or lack of confidence
barriers to use of the Act
competency
confidence
consequences of education
experience of others
extra support around MCA
knowledge
lack of experience
limits to knowledge
peer support
philosophy of the Act
self directed learning
training
training had
training needed
values and principles
what helps

6. Subjectivity
assessing capacity or best interests
anxiety or lack of confidence
autonomy
avoiding trauma
best interests
blood pathway
challenging others
checking
client understanding
communication problems
concept of the decision (size or effect)
consent issues
consequences of education
contentious issues
decision making
dilemmas, conflicts and competing imperatives

documenting
formal versus informal
gaps in knowledge and training
gathering evidence accurately
grey areas
known to interviewee or not
least restrictive
Making decisions quickly
other agendas
peer support
practice
problems with decision making
querying decisions
responsibility for case or decision
safety
to use the Act or not
triggers to intervention

7. Risk reducing strategies
assessing capacity or best interests
anxiety or lack of confidence
best interests
checking
competency
confidence
consequences of education
decision making
deferred responsibility
education
empowerment
experience
extra support around MCA
formal versus informal
framework
gathering evidence accurately
grey areas
hiding behind others
information gathering
justifying decisions
known to interviewee or not
peer support
performance management
practice
risks
safe practice
safety
simplifying the process
supervision or mentor
support of team
transparency
what helps

8. Significance of decision
assessing capacity or best interests
autonomy
avoiding trauma
best interests
blood pathway
client descriptors
client understanding
concept of the decision (size or effect)
consent issues
consequences of intervention
consequences to client
considering the needs of others
decision making
description of the decision to be made
difficulties in assessment
dilemmas, conflicts and competing imperatives
documenting
ends justifying means
experience
formulation or hypothesis offered for client problems
grey areas
human rights
implications of decision
intervention
least restrictive
Lengthy process
Making decisions quickly
medication
other agendas
peer support
practice
problems with decision making
reassuring the client
responsibility for case or decision
safe hold
safety
service users opinion
structured clinical judgement
support for client
to use the Act or not
triggers to intervention
unwise decisions

9. Family involvement
assessing capacity or best interests
avoiding trauma
barriers to use of the Act
best interests
blood pathway
challenging others
client descriptors
client understanding
communication problems
concept of the decision (size or effect)

consequences of intervention
consequences to client
considering the needs of others
decision making
difficulties in assessment
discrimination and abuse
family involvement
information providing
intervention
known to interviewee or not
legal services, solicitors, lawyers, appointees
other agendas
supporting families
what helps
what hinders

10. Context
assessing capacity or best interests
autonomy
avoiding trauma
barriers to use of the Act
best interests
blood pathway
client descriptors
client understanding
consent issues
consequences of intervention
consequences to client
considering the needs of others
dangerous or problematic practice
decision making
difficulties in assessment
discrimination and abuse
ends justifying means
factors that affect capacity
force or against will
formal versus informal
formulation or hypothesis offered for client problems
illegal or unlawful practice
intervention
justifying decisions
known to interviewee or not
legal services, solicitors, lawyers, appointees
long term decision making
MCA safeguarding
other agendas
peer support
problems with decision making
protection
risks
safeguarding
service users opinion
support for client
transparency

11. Level of disability
assessing capacity or best interests
autonomy
avoiding trauma
best interests
blood pathway
client descriptors
client understanding
consent issues
consequences to client
dangerous or problematic practice
decision making
difficulties in assessment
factors that affect capacity
grey areas
information providing
other agendas
problems with decision making