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Learning disability nurses' experiences of promoting autonomy in adults with profound and multiple learning disabilities: A phenomenological study.

Pedzai Tsungu

Thesis is submitted for the award of

Master of Science by Research

The degree is awarded by the University of Huddersfield,

Institute for Research in Citizenship and Applied Human Sciences (IRCAHS),

Centre for Health and Social Care Research,

Huddersfield, United Kingdom

9 June 2014

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Abstract

This thesis reports on a year-long study seeking to explore Learning Disability (LD) nurses lived experience of promoting autonomy for adults with profound and multiple learning disabilities (PMLD) who live in England. Promoting autonomy constitutes a key component of LD nurses' role within the current service provision for this client group. The question of how much autonomy is allowable while ensuring the safety of this client group remains an ethical problem and one for which no ultimate solution exist. Exploring LD nurses lived experiences produces a special kind of 'practical' knowledge that is beyond the dominance of medical knowledge and well-grounded in their day to day experiences. Findings will therefore be more meaningful to LD nurses regarding promoting autonomy for adults with PMLD as their experiences are explicated and illuminated. Consequently, potential exists for findings of this study to contribute to LD nursing discipline's knowledge base and evidence-based-practice. A Heideggerian hermeneutic phenomenological framework of inquiry was used to guide the inquiry. Data were gathered from LD nurses using individual face-to-face unstructured interviews. Broad open ended questions were used to obtain participants' concrete descriptions of their experiences in relation to promoting autonomy for adults with PMLD. Nine LD nurses from the north of England were interviewed and interviews were audio recorded and transcribed verbatim to create textual basis for data analysis. Data were analysed following a discursive and iterative seven step procedure as described by Diekelmann, Allen, and Tanner (1989). Analysis of participants' interviews revealed three themes: (1) taking responsibility, (2) care delivery and (3) personhood. The findings illustrate how participants take pride in their role as learning disability nurses and the value they place on collaborative team working as well as the importance of knowing the person as an individual with own personality, behaviours and character in promoting autonomy for adults with PMLD. The results are relevant to LD nursing practice and also to cares and other health and social care professionals who work with adults needing support in most aspects of their lives such as those with progressed dementia and brain injury.

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Abbreviations

AAO: Action for Advocacy Organization

CINAHL: Cumulative Index to Nursing and Allied Health Literature

DH: Department of Health

EBP: Evidence-Based-Practice

HP: Hermeneutic Phenomenology

HR: Human Rights

LD: Learning Disability

MCA: Mental Capacity Act

NHS: National Health Services

NMC: Nursing and Midwifery Council

PCP: Person Centred Practice or Person Centred Planning

PMLD: Profound and Multiple Learning Disability

RCN: Royal College of Nursing

RN: Registered Nurse

RNLD: Registered Nurse (Learning Disability)

SREP: School Research and Ethics Panel (University of Huddersfield)

Definition of Terms

Dasein: Mode of existence referring to a nature of human qualities that emphasizes its individuality and its role in the disclosure of being.

life-world: Thereness

Bracketing: Identifying and suspending one's own previously acquired knowledge, beliefs, and opinions about a phenomenon under study to achieve a state of transcendental subjectivity (neutrality).

Lebenswelt: life-world and as above means thereness

being-in-the-world: Person in their natural world or setting. Used synonymously with ***person-in-context***

fore-having: A person's assumptions or preconceptions of topic of interest derived from previous lived experience. Used synonymously with ***fore-sight*** and ***fore-conception***.

***There-being*:** The ontological/existential nature of *Being*.

Being: Human qualities.

Embodiment: Mode of Being that includes an understanding of embodied knowing that encompasses skilful comportment and perceptual and emotional responses.

***Throwness*:** Thrown into the world. The person is thrown into a particular body, a particular time, a particular culture or a particular set of prevailing socio-cultural attitudes and mores, stances and opinions.

Chapter 1

Introduction

1.1. Introduction

This chapter details how my interest on the research topic developed and provides background information on the research topic to highlight its context and the significance of research question to be addressed. An outline of the structure of this thesis is then presented under the headings of literature review, methodology, findings, discussion and conclusion.

1.1.1. Researcher's prior knowledge of research topic

A first person narrative will be used in this part of the thesis as it is a reflective account of the researcher's knowledge, understanding and experiences regarding the topic being studied. This study used a particular interpretive framework of inquiry and it has been argued that meanings are co-constituted by participant and the researcher's contexts and interaction of the two during the research process (Wojnar et al, 2007; Moran, 2000). It is therefore important that the role of the researcher and the influence of his own pre-conceptions, social and cultural conditioning is established in first person (Corbetta, 2003; O'Brien, 2003; Moran, 2000). Finlay explains that researcher involvement in an interpretive approach to inquiry can never be impartial and objective as they bring to the process of interpreting their own perspectives, history, beliefs, prejudices and predispositions. By making the background assumptions explicit, O'Brien (2003) argues that the researcher can test assumptions and new knowledge emerging from the study's findings. Also equipped with this knowledge, the reader will be able to reach an informed decision on the extent to which the researcher have gone to avoid tainting and dominating research results with own predilections and prejudices (Finlay, 2011).

My interest on Learning Disability (LD) nurses lived experience in promoting autonomy of adults with profound and multiple learning disabilities (PMLD) developed from my first hand experiences

of working as an LD nurse in a community based service for adults with differing levels of learning disabilities and additional needs. As an LD nurse, I believe promoting and safeguarding autonomy of this client group holds a central position in articulation of my day to day tasks and obligations. It is also my personal commitment to lessen the burden of living with a disability and I have been involved in exploring alternative communication technology for a client with a degenerative neurological condition affecting speech, facilitated a person centred planning (PCP) meeting for another client and the list goes on. Common to these experiences is that they are all underpinned by the concept of autonomy which will be explained in sections to follow. Also from personal and professional reflections and engagement with extant literature at both philosophical and practical knowledge level, the breadth and depth of the concept of autonomy unfolded before me to reveal a rather complex phenomenon and yet part of my taken for granted day-to- day practice as an LD nurse.

Currently I am working directly with adults with PMLD within a philosophy of care that embraces the concepts of individualism, right to choices and civil liberties, inclusion and involvement achieved in many ways including collaborative and partnership working with other health and social care professional, clients and their significant others. Awareness of contextual issues that I have to work within including professional and ethical commitments, legal obligations, policy mandates at both national and local level, societal perspectives and expectation together with beliefs and values of the clients I support and those of myself steered my interests towards exploring LD nurses' lived experience of promoting autonomy for adults with PMLD. However, I must acknowledge at this point that potential for bias exists in conducting this research qualitatively. Marotzki (2004) highlights that qualitative research acknowledges this potential for bias as researchers are influenced by their own beliefs and feelings about topic being studied. The following sections will now clarify what is meant by 'LD nurse', 'profound and multiple learning disabilities' and 'promoting autonomy'

1.1.2. Learning disability nurse

For the purpose of this study, what defines an LD nurse has been derived from Nursing and Midwifery Council (2010) register. An LD nurse is one with current registration under the LD nursing parts of the register. The register maintains three categories; RN5: learning disabilities nurse, level 1, RNLD: learning disabilities nurse, level 1 and RN6: learning disabilities nurse, level 2. NMC (2010) describes the role of LD nurse as caring for people of all ages with a learning disability involving promoting their autonomy, rights, choices and their social inclusion in the health care system. Participants may hold other qualifications and these will not be referred to in the study. However, those holding managerial posts and nurses from other disciplines who work with adult with PMLD were excluded due to the limited scope of the study to handle stratified data.

Under the current service provision for people with learning disabilities, LD nurses occupy the very heart of initiatives and service development for this client group and promoting autonomy constitute a fundamental role (Schipper, 2011; NMC, 2010; RCN, 2010; Wullink et al, 2009; Moulster and Turnbull, 2008; Gates 2002).

1.1.3. Adults with profound and multiple disability

The term ‘profound and multiple learning disabilities’ (PMLD) will be used throughout this thesis with knowledge that elsewhere in literature different terminologies have been used. In England, the Department of Health (2001) used the term ‘learning disability’ within their policy and practice documents. However, the term ‘intellectual disability’ is becoming more increasingly known internationally (Johnson and Walmsley, 2010). The researcher understands that readers may hold different views and acknowledges that using either of the two terms contributes to the process of labelling. Johnson and Walmsley (2010) acknowledge the controversy that use of any label attracts and that by using any such labels, they will also be playing a part of the labelling process. Labels are often devaluing or demeaning but can also act as an indicator for specific needs and desires of individuals or a group (Johnson and Walmsley, 2010).

Adults with PMLD have a primary diagnosis of a learning disability. The UK Department of Health (2001) describes a person with a learning disability as one with a significantly reduced ability to understand new or complex information, to learn new skills and a reduced ability to cope independently which starts before the age of 18 with lasting effects on development. According to World Health Organization (2010), a person is considered intellectually disabled if he or she has an IQ score less than 70 to 75. A learning disability can be mild, moderate or severe and profound depending on severity. Moving across the continuum from adults with 'mild' to those with a 'profound' learning disability, self-care capacity is depleted as does communicative and cognitive abilities. Adults with PMLD are not a homogenous group. Goode (1997) characterises a person with PMLD based on two extremes; on one end is as one who has a speaking vocabulary of over 300 to 400 words and uses grammatically correct sentences or may use gestures, understands simple verbal communications including directives and questions while on the other end is someone who may lack any formal symbolic vocal or gestural language and communication may be pre-symbolic or action based , idiosyncratic and from the perspective of carers, entirely absent. Promoting autonomy of adults with PMLD can be a complex undertaking for LD nurses not only due to high level of dependency and co-existence of multiple needs, but also due to a history of low expectations, the effects of ageing, societal discrimination and prejudices as well as the very nature of learning disability practice in terms of its own history, lack of clear definition and constant subjection to political and media scrutiny (Mitchell, 2004).

Adults with 'profound' learning disabilities also tend to have additional needs including physical disabilities, very limited speech, sensory impairment, altered levels of concentration, poor memory, challenging behaviours and mental health needs, chronic health problems and epilepsy (Devi, 2013; Petry et al, 2004; DH, 2001). They also experience the same effects of ageing as any other individual from the general population such as increased dependence on others, impoverished social circles of support and dementia all to the detriment of their capacities to act autonomously. The adult with PMLD therefore has to overcome a series of multiple disabilities, effect of biological

processes such as ageing, societal barriers including discrimination, and prejudice to exercise his or her autonomy. Reinforced by difficulties in communication abilities, this and according to the view of Petry et al (2004) and in large part, makes them a unique group from people with milder or without disabilities.

1.1.4. Promoting autonomy

Current policy and legislative framework guiding LD nursing practice in England stipulates that adults with PMLD must be supported and empowered to exercise their autonomy in all aspects of their lives including health, welfare and finances (DH, 2009, 2001; SEU, 2005). The concept of autonomy is already a key principle in nursing ethics and has become an important issue for people with learning disabilities in terms of service delivery style and its nature (Schipper, 2011; DH, 2009; Wullink et al 2009). While there have been significant improvements in achieving these goals, Mansell (2006) points out that there are still gaps and unevenness in their attainment particularly for adults with PMLD. RCN (2010) notes that as in the past and even more frequently now, this client group continues to be subjected to exclusion and discrimination.

Within the context of this study, the phenomenon of 'promoting autonomy' has been interpreted and operationalized to broadly mean an action or nursing intervention, in isolation or combination, that has actual or perceived outcome intended to promote and safeguard the rights, beliefs, values and wishes of adults with PMLD. This has been derived from the Government white paper Valuing People (2001) and Valuing People Now (2009) as well as Mental Capacity Act (2005). For example, Section 2 of the MCA (2005) provides for the kinds of support for decision-making which can be given by other people in helping an adults deemed to lack capacity preserve their autonomy. This include providing accessible information, acknowledging the individuals wishes and preferences, involving trusted people and paying attention to where and when the decision is going to be made.

The concept of autonomy has multi-perspective definitions based on legal competence (Van Hooren et al, 2002), empowerment and citizenship (Tauber, 2001; Shephard, 1998), moral values (Meininger, 2001), professional duty of care (Van Hooren et al, 2002), ethical principles (Streubert and Carpenter, 2011; Beauchamp & Childress , 1994), self-determination and independence (Wehmeyer et al. 1996), individuality (Tauber, 2001), control (Wolfensberger & Glen 1975) and self-realisation (Emanuel & Emanuel 1992) among many others. This has been attributed to society becoming increasingly multiculturalism, democratised and pluralistic in its make up together with more tolerance for widely diverging moral systems (Tauber (2001). To a greater extent, this has attracted some difficulties to LD nursing practice as nurses are faced with the dilemma of basing their decisions on more than one perspective and all of which are equally valid.

Dunn et al (2007) highlight that for some individuals with learning disabilities, the nature and severity of their disability means they will be unable to make one or more autonomous decisions in their lives regardless of the support they receive. This is particularly true for adult with PMLD owing to cognitive and communicative impairment and other co-existing physical and health needs. According to Wilson and colleagues there is a mismatch between theoretical literature in learning disabilities and professional codes of practice drawn based the assumption that the person with learning disabilities is autonomous and the reality of promoting autonomy for those with learning disabilities and in particular those who are profoundly disabled and completely dependent on others. Dunn and colleagues go on to point out that set against service frameworks founded upon the pretext of independence and self-determination, this give rise to dilemmas in which conflicting discourses of autonomy, protection and risk taking lead to restrictions in the range of choices available to this client group. Similarly, findings from a study by Wilson et al (2008) exploring the experience of professional from adult learning disability service who consulted with Local Ethical Advisory Groups addressing an ethical issue within their line of work revealed systematic pressure on the professionals to find definitive solutions to such ethical dilemmas when the issues were not open to such resolution.

1.2. Background and context of research

History of people with learning disabilities is that of institutionalised care, characterised by low expectations, denial of opportunities and experience of everyday life, isolation and disablement, little individualism and inhuman treatment that was unilaterally informed and dominated by the doctrine of medical paternalism (Markwick and Parrish, 2003; Shepheard, 1998). Markwick and Parrish (2003) argues that institutions served the interest of the society and not their inmates while Brewster and Ramcharan (2010) point out that professional control dominated lives in these institutions. The prevailing ideologies of eugenics encouraged the imposition of repressive and abusive practices towards people with learning disabilities but these have since been moderated after the Second World War (Burrell and Trip, 201). Continued shift in service provision philosophy, political landscape, social discourses towards people with learning disabilities and changes to beliefs and value systems underpinning LD nursing practice resulted in closure of institutions and relocation of the institutions' inmates into small community based establishments.

Since deinstitutionalisation, continued arguments are that not all of those relocated to smaller residence in the community have been allowed to fully experience the proposed ideology of 'community living' 'ordinary lives' as some community based establishments are as rigid and restrictive as those of large institution (Kearney and McKnight, 1997; Brown, 1991). The majority of adults were resettled in nursing homes and theses have come to be labelled as a metamorphosis of the large institutions into little institutions. Waker et al (1995) describe nursing homes as institutions whose role is only to care and which therefore encourage and foster dependence rather than independence; where even the most basic decisions, such as when and what to eat, are taken away from people. This description was born out of a perceived analogy of boredom, isolation, lack of involvement in meaningful activities and lack of interaction with staff or care givers experienced by people with learning disabilities living in long-term nursing homes (Emerson et al, 1993). Waker and colleagues (1995) argue that if adults with learning disabilities are to have positive futures, then

it is implicit that service provision agencies and healthcare professional alike view and treat each person as an individual with special needs. Emerson et al (1993) view the pitfalls as a personnel issue for people with learning disabilities to be addressed and commented that if services are not responsive to the needs of this client group, new institutions will be formed in the community. Lack of staff training, limited financial resources, prejudice and discrimination and inequitable access to health-care services in the community are among many issues that continue to challenge and threatens the ideals of community living, citizenship and most importantly of the autonomous self of adults with PMLD (Leeder and Dominello, 2005). In setting out priorities for the future development of learning disability services, Mansell (2006) identifies the need for a renewed focus and genuine determination on improving the quality of life of persons with learning disabilities together with a change in the role of staff to being more facilitative and enabling towards the individual, especially those with profound learning disabilities.

LD nursing is a relatively small branch of nursing and sits on the margins of nursing discipline in England and generally, there has been very little research into the lived experiences of LD nurses who work with adults with PMLD (Mitchell, 2004). Raghavan and Patel (2008) acknowledge the need professional knowledge base of learning disability nursing in order to strengthen its professional identity and to enhance its growth. Peplau (1988) proposes development of a practice-based theory and urges nurses to use nursing situations as a source of experiential learning and development of unique nursing theory. Raghavan and Patel (2008) explains that this places emphasis upon the need for LD nurses to understand, internalise and act upon the general principles gained from experiential learning. Annells (1999) asserts that understanding of lived experiences of LD nurses facilitates adequate development of nursing discipline knowledge, theories and models well ground in concrete experiences. Moreover, adults with PMLD are a diverse group and just like everyone else, they have their own history, personality and characteristics, values and opinions that need to be respected and are in constant change thereby challenging the Learning Disability nurse

not only need to be responsive and adaptive but also to be creative, perceptive and sensitive in their ways of working if they are to adequately meet the needs of this client group.

Similarly, the philosophy and approach to supporting people with learning disabilities are in a process of constant change (Kay, 2003). However, this does not detach it from its own history and exploring and understanding the LD nurses' insights, perceptions and meaning of their experiences in relation to promoting autonomy of adults with PMLD is important as it has the potential to uncover and illuminate taken for granted meanings and perceptions of their practice. However, there has been very little research into the experiences and perceptions of LD nurses and in particularly those who work with adult with profound and multiple learning disabilities (Parahoo, 2006; Turnbull, 1997).

Both the HR Parliamentary committee 7th report (2013) and the Learning Disability Task Force (2004) identifies those with multiple, complex support needs as benefiting least from current policy initiatives. It is therefore important that action is taken to understand and explore LD nurses' lived experience of promoting autonomy of adults with PMLD. Understanding LD nurses experiences and perceptions, meaning and understanding of those experiences is important to LD nurses themselves as well as to the services and to people with learning disabilities (Dinkel, 2005; Mitchell, 2004). In light of the uniqueness of learning disability nursing to the UK, Griffiths et al (2007) and Doody et al (2012) advocate that LD nurses need to create sound accessible research-based evidence that seeks to capture and illuminate the essence of Learning disability nursing.

1.3. The aim of the study

The aim of this study is to explore LD nurses lived experiences of promoting autonomy for adults with PMLD who live in England.

1.3.1. The study's objectives are:

To access and obtain learning disability nurses' naive descriptions of their experiences of promoting autonomy for adults with PMLD.

To critically analyse learning disability nurses' understandings and interpretations of their lived experiences regarding promoting autonomy for this client group.

To derive essential meaning of the nature of LD nurses' experiences in relation to promoting autonomy of adults with PMLD.

1.3.2. The research question

The study was designed to answer the following question;

> *What are the experiences of learning disability nurses regarding promoting autonomy for adults with profound and multiple learning disabilities in England?*

1.5. Structure of thesis

This thesis contains six chapters:

1.5.1 Chapter 1: Introduction

This chapter introduces the whole thesis and sets out what the study seeks to investigate after establishing background and context to the research question, aims and objectives to be addressed.

1.5.2. Chapter 2: Literature review

The purpose of this chapter was to locate the research project, form its context and provide insights into previous work on the topic being investigated. The literature review integrates this study with the broader literature and research already published.

1.5.3. Chapter 3: Research Methodology

The purpose of this chapter was to describe the research methodology used within this study, explaining the sample selection, how data were collecting and analysed. This chapter also provides an outline of measures taken to ensure ethical treatment of participants together with how threats to the soundness and rigor of research methods were addressed.

1.5.4. Chapter 4: Findings

This chapter presents findings of this study using themes and meaning categories. Interview excerpts are used to illustrate how the themes and meaning categories have been derived.

1.5.5. Chapter 5: Discussion

Findings form this study are discussed in light of extant literature, researcher's own pre-understandings of the topic being investigated and participant's context.

1.5.6. Chapter 6: Limitations, recommendations and conclusion

This chapter presents a summary of the major findings of this study, identifying limitations to the study and recommendations that emerged as a result.

Literature review

2.1. Introduction

The purpose of this literature review was in threefold: (1) to explore the conception, interpretation and application of the concept of autonomy among adults with PMLD, (2) to explore the LD nurses lived experiences regarding promoting autonomy of adults with PMLD and (3) the history of people with learning disability in relation to promoting autonomy of this client group. This will illustrate the complexities whilst bringing dilemmas and conflicts that LD nurses experience in promoting autonomy of adults with PMLD to the fore. This was achieved by conducting an integrative review of both primary and secondary literature including computerised searches of databases such as CINAHL, PubMed and Scopus together with hand searching of journals and textbooks in the library.

The National Nursing Research Unit at King's College London (2007) conducted a literature review in order to evaluate the nature and scope of research available within the spectrum learning disability nursing practice. The review found fewer than 200 studies. The majority of the research came from the UK. Much research is descriptive and only a minority of studies evaluates direct intervention or delivery of care by LD nurses. However, in the 90s a number of studies explored the experiences of transition from institutionalised care system to community based care for adults with LD. The majority of these were case studies and addressed aspects of promoting autonomy such as advocacy and citizenship. The implementation of Mental Capacity Act (2005) saw further studies which sought to explore aspects of autonomy but were limited to the concept of 'best interest' (MCA, 2005). This research study seeks to explore LD nurses experiences of promoting autonomy for adults with PMLD.

2.2. Defining autonomy

In theory, defining autonomy has never been easy and no unified definition exists. An extensive literature review by Wullink et al (2009) considered four definitions. The first definition proposed by Wehmeyer et al (1996) refers to autonomy as self-determination and independence demonstrated by a set of behaviours or acts that constitutes one's own preferences, interests, and/or abilities. Independence signifies freedom from undue external influence or interference. In the definition by Wolfensberger & Glen (1975), autonomy is understood as control where a client has the same amount of control over his actions, decision-making, wishes and desires as any other person of comparable age. Thirdly, autonomy is viewed as a characteristic of client history, consisting of three dimensions: self-determination, independence and self-care. Emanuel & Emanuel (1992, p. 2225) propose a fourth perspective and view autonomy as moral self-development or self-realisation with responsibility placed upon the client;

> *'to critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realise values'.*

Wullink et al (2009) consider the definition of autonomy by Wehmeyer et al (1996) as a starting point for their literature review as this definition was formulated with people with learning disability in mind, focusing on their behaviour and their skills. In addition to the two elements self-determination and independence from Wehmeyer et al (1996) definition, Wullink et al (2009) included self-regulation and self-realisation to constitute a four element model of autonomy that they believe will be more applicable to health among people with intellectual disability. Wullink and colleagues conclude that elements of this model such as self-determination can be taught in nursing practice. However, Dunn et al (2007) highlight the fact that owing to the nature of their disability, some men and women with learning disabilities will be unable to make one or more autonomous decisions at certain points in their lives, opening up an area of difficulty for LD nurses

working in services developed on the pretext of expanding and promoting autonomy of people with LD including adults with PMLD.

Davies et al (1997) acknowledges the difficulties in conceptualisation and operationalization of autonomy in nursing and stresses on the importance of diligence in its definition if practices which might promote autonomy and independence are to be identified. Tauber (2001) suggests that nurses must seek to become fully illuminated and educated to the complexities of those practices, reminiscing on matters of fact including social and political implications and history of the problem. Changes in definition of learning disability, social constructs and support systems precipitated by altered perceptions towards people with learning disabilities have and continues to make the applicability of the concept of autonomy in the care of people with learning disabilities a difficult undertaking (Meininger, 2001; Ray,1994; Luckasson, 1992). Ray (1994) comments that by recognising the influence of context, historical meaning and the local world, experiences could be interpreted and understood in a new way. The aim of this study is to explicate lived experiences of Learning Disability Nurses in relation to promoting autonomy of adults with PMLD. In nursing, this is key in finding new understandings of practices, particularly those actions that go unnoticed and seek improvements (Parahoo, 2006).

Beauchamp and Childress (1994, p125) contend that respecting one's own autonomy in healthcare is to acknowledge a person's right to hold views, to make choices and to take actions based on personal values and beliefs. This was collaborated by van Hooren et al, (2002) who state that in contemporary ethical debates, autonomy is opposed to paternalism and places emphasis on freedom of choice, without external interference. Similarly, Streubert and Carpenter (2011) refers to the concept of autonomy as an ethical principle that encompasses the notion of being a self-governing person with decision-making capacity. Meininger (2001) and Tauber (2001) views the elaboration of individuality as being autonomous and asserts that the individual's capacity for active, independent, self-conscious and rational self-determination constitute the main presupposition of

autonomy as a central moral value. However, defining autonomy in terms of decision-making capacity, freedom from others and self-governance has significant implications to learning disability nursing practice and service delivery to adults with PMLD. In adults with PMLD, impairments to decision-making capacity as caused by limitations in understanding or using relevant information in reasoning disenfranchising them from attaining full autonomy (Ashley, 2012). Petry et al (2004) state that the high level of dependency, complex and specific needs together with low level of functioning among the population of adults with PMLD as reinforced by communication difficulties in expressing needs are major contributors to difficulties experienced by LD nurses' in promoting autonomy of this client group. Mansell (2006) identify misunderstanding of the needs of PMLD, service provision and needs mismatch, prejudice, discrimination and low expectation, marginalization, isolation, dehumanisation, misdirected pity, negative strategies and values as other contributory factors. LD nurses will therefore need to constantly adjust their attitudes and moral compass in light of emerging understandings and conceptions of how disability is defined and the nature and style of service delivery including access to rights, choices and civil liberties by adults with PMLD (Tauber, 2001). Tauber suggests that LD nurses must therefore seek to become fully illuminated and educated to the complexities of their decision and actions, reminiscing on matters of fact including social and political implications and history of the problem.

2.3. Autonomy and citizenship

Lowden (2002) defines autonomy as an individual's ability to make self-determining choices and involves independence as well as the capacity to reason and decision-making ability. This definition is synonymous with the underpinning ideologies of citizenship, a concept that emphasises freedom of choice without external interference and realization of the self into a sovereign and self-governing individual (Meininger, 2001; Tauber, 2001; van Hooren et al, 2002). As citizens, adults with PMLD have the same fundamental rights and responsibilities just like any other person of the

same age, to make their own decisions based on their subjective values (Schipper, 2011; RCN, 2010; Morser et al, 2009; Wullink et al, 2009; DH, 2009, 2001; MCA, 2005; Human Rights, 1998). The precept of adulthood is a concept that carries connotations of productivity including self-governance, non-dependent economic self-sufficiency, family roles and full personal autonomy. Morris (2005) posits two main perspectives on citizenship, an individualistic approach, where the nature of citizenship is determined by an individual's capacity to make choices and a structuralist approach where social and economic factors are considered to have a greater influence on individual action. Vorhaus (2006) believes that conception of citizenship and adult status like these subjects adults with a learning disability to a double jeopardy as such roles and levels of autonomy may not be possible in our society.

The notion of citizenship does however recognise and appreciate the fact that certain individuals of our society may require support to enjoy and access their rights and civil liberties. In learning disability nursing practice it can be argued that the notion of support is of particular relevance to the care and support of adults with PMLD who are often dependent on others for almost all aspects of their lives. However, Disability Rights Commission (2005) reports that too often choices and options for disabled adults are limited and circumscribed by those in position of power. Critiques of the traditional caring relationship of protection, dependency and paternalism has led to the conception of a citizenship paradigm that stresses on people learning to live a meaningful life, and get supported in this process (Schipper et al, 2011).

Recognition that adults with PMLD will need support to make autonomous decisions has led to the development of a new role for LDN as an advocate. O'Brian and Kumuravelu (2008) highlighted the importance of this role for people with learning disabilities who may not always be able to self-represent in the process of deciding requiring support and advocacy to uphold their autonomy. However, advocacy itself is a very controversial concept in nursing practice. A qualitative study by Blackmore (2001) using semi-structured interviews explored the perceptions of learning disability

nurses about their advocacy role and findings showed that nurses used the term ‘advocacy’ to describe a variety of activities that are underpinned by the opposing ethical principles of autonomy and paternalism. Blackmore argues that using the term ‘advocacy’ to describe actions underpinned by these opposing ethical principles is perhaps the root cause of many of the conflicts and problems identified by learning disability nurses about their role in client advocacy. Moreover, being an advocate may bring the LDN into conflict with the public, the service user, the employer and the profession when views differ. Blackmore’s findings highlights the complexities of trying to consolidate ideals of promoting autonomy and that of advocacy in current nursing policy, and calls for an urgent need for learning disability nurses to debate the issue of nurse advocacy and influence policy in this crucial area. Sanderson (1995) point out that the key challenge for the nurse is in finding a balance between informed choice and what is in the person’s best interest when helping people to advocate for themselves.

A case study by Clichton (1998) describes a man with severe intellectual disability who lacked the capacity to decide upon many of the basic choices of everyday life and illustrates how misinterpretation of, and conflicting philosophy of care can result in parentalistic over-control being replaced by under-control. The man had been resettled in a community based group home following 20 years of institutional care and his health was deteriorating, losing weight progressively as well as spending most of his time in bed. There was resistance from staff at the home to his readmission to the same hospital for assessment on the understanding that it was his choice not to attend hospital appointments. Clichton commented that there was a fundamental error in the group home's philosophy of care in that the case illustrated a false view of the principle normalization that encourages the maximization of normality. A qualitative research study Wilson et al, (2008) explore how professionals bridged mismatch between professional codes of practice which assume clients to be autonomous and the reality of fostering autonomy for people with learning disabilities who at times are completely dependent on others. Nine professionals from adult learning disabilities services who had consulted with local Ethical Advisory Groups were interviewed about their

experience of addressing an ethical issue within their work. Findings revealed systemic pressure on professionals to find definitive solutions to ethical dilemmas when the issues were not open to such resolution. Consequently, LDNs are faced with challenges and dilemmas in comprehending on decisions upon which definitions of autonomy are based. Wilson et al, (2008) conclude that professionals need to draw on ethical frameworks that can accommodate relational aspects of their practice. Hewitt-Taylor (2003) also proposes the need for nurses seeking to promote the individual's autonomy to consider how the ethical basis of autonomy interlinks and to be aware of potentially differing interpretations that they may encounter in practice. The importance of this is captured in the words of Wolfensberger (2002, p. 254);

> *What ultimately determines how a person or a group will be treated, and what others will afford to such a party in life, is what is in the mind of those who do the treating and affording …….. and to what degree they perceive the party in a valued social role.*

2.4. Learning disability nursing and adults with PMLD

In marking a century since the implementation of the 1913 Mental Deficiency Act, O'Driscoll (2013) claims that it is one of the most significant pieces of legislation in the care and support of people with learning disability. The eugenic ideologies dominated the views people held about people with learning disabilities before the Act particularly that 'mental deficiency' could be transmitted between generations resulting in their jailing and long-term admission into workhouses and asylums (O'Driscoll, 2013). As well as society's assumptions, the political landscape played a key role in separating and isolating people from the community (Waker et al, 1995). Living in the institutions meant that adults with PMLD were deprived of their civil liberties and rights, of their individuality, of their dignity, of their choices and of opportunities and experience of everyday life (Burrell and Trip, 2011; Brewster and Ramcharan, 2010; Markwick and Parrish, 2003; Crichton, 1998). As a result people with learning disabilities living in these institutions were rendered powerless and non-citizen.

Institutions have since been closed following a progressive shift in society's attitudes towards people with learning disability. The closure of large institutions and move of people with learning disability into community based dwellings was seen as a fundamental ideological change that will afford this client group autonomy and self-determination (Boyle, 2007). However, since deinstitutionalisation, critiques such as Beadle-Brown et al (2007), Leeder and Dominello (2005), Kearney et al (1995) and Brown (1991), have argued that not all of those relocated to smaller residence in the community have been allowed to fully experience the proposed ideology of ordinary lives as some community based establishments are as rigid and restrictive as those of large institution. This has led to Sacco-Peterson (2004) describing nursing homes as smaller institutions associated with limited ability to control one's own routines owing to depleting self-care capacity and environmental constraints. This description was borne out of a perceived analogy of boredom, isolation, lack of involvement in meaningful activities and lack of interaction with staff or care givers experienced by people with learning disabilities living in long-term nursing homes (Emerson et al, 1993). The authors viewed the pitfalls as a personnel issue for people with learning disabilities to be addressed and commented that if services are not responsive to the needs of this client group, new institutions will be formed in the community. Lack of staff training, limited financial resources, prejudice and discrimination and inequitable access to health-care services in the community among many other issues challenges continues to threaten the ideals of community living, citizenship and most importantly of the autonomous self (Beadle-Brown et al, 2007; Leeder and Dominello, 2005).

The Government's White Paper Better Services for the Mentally Handicapped (DHSS, 1971) and in acknowledgement of this change in society's views towards people with learning disabilities set about on plans to half the population of people with disabilities living in hospitals and relocating them into community based establishment. According to Dunn et al (2007), the 'ordinary life' philosophy has been embraced by government policy in the UK in developing services, and has informed the White Papers, Valuing People (DH, 2001, 2009) which is underpinned by the government's ambitions to advance the quality of life of people with learning disabilities through

respecting their rights to choice, citizenship, inclusion and independence. The result was a significant shift from deontological-based nursing practice to rights- based and community oriented care delivery and service systems (Whitehead et al, 2008). This change in service culture and philosophy meant a new role for Learning disability Nurses, one that is characterised by fostering autonomy, empowerment, involvement, inclusion, partnership and person centred practice (Crichton, 1998).

An illustration of the complexities of promoting choices and autonomy during deinstitutionalisation was made by Markwick and Parrish (2003) using three case studies. They described the experience of relocating learning disability services into the community as a journey for both the service user and the carers. The service user had to learn about dealing with exposure to choice and autonomy while the organisation and its personnel had to reconstitute from the institutional paradigm into philosophy of care that values the individual. This is consistent with Mansell's (2006) recommendations in setting out priorities for the future development of learning disability services. Mansell identifies the need for a renewed focus and genuine determination on improving the quality of life of persons with learning disabilities together with a change in the role of staff to be more facilitative and enabling towards the individual, especially those with profound and multiple disabilities. As LD nurses became educated about their experiences in relation to promoting autonomy of adults with PMLD, a point of mutual respect and understanding may be reached between the individuals and the nurse. Markwick and Parrish (2003) argue that this will remove or lessen organisational barriers and facilitates increased service user involvement in their care.

Research into learning disability nursing since 1990 provides a mixed view. One of the major conclusions from an extensive study by Clifton et al (1992) was that learning disability nursing practice reflected the then current philosophies of supporting people with learning disabilities. According to the researchers, this meant that nurses were supporting the rights and choices of individuals and supporting them to live in community settings. Findings by Norman et al. (1996) in

a study where expert informants were asked to report on the relevance of nurse education in learning disability confirmed this. Promoting autonomy was one of the main functions of the nurses identified with the other two being supporting self-advocacy and assessing needs. Government documents such as Meeting Needs through Targeting Skills (DH, 1995) highlighted key changes to the role of learning disability nurse. The document proposed that the purpose of nursing for people with learning disability is to work collaboratively with the individuals to improve their personal autonomy. However, Mitchell (2004) argues that the term "nursing" is at variance with the work that learning disability nurses do. This has led to unease about the work and its professional location within nursing. Mitchell cited the difficulty of reconciling definition of learning disability nursing and reality and the threat to the continuation of the specialism. On the contrary, Moulster and Turnbull (2008) contends that far from its lack of definition being a disadvantage it is precisely this absence of defined role and of theory that enables it to adapt to the changing needs of the service.

Current LD nursing service provision in England is informed by Government's Whit Paper Valuing People (2001) and later Valuing People now (2009) aimed at enabling people with learning disabilities to experience a good quality of life and that they lead active and fulfilling lives in the community with more control over their own destiny, which they have been denied in the past decades (Markwick and Parrish, 2003). This was expressed in terms of three main principles; independence, choice and inclusion (Markwick and Parrish, 2003). Although policy had changed, Markwick and Parrish points out that the pace of change involved in developing a new culture for the care of people with a learning disability has required a radical revision for many of personal attitudes and customs and managerial practices. The change in culture brings new challenges to staff, LD nurses had to examine, challenge and often change their own value systems and Markwick and Parrish believe that as nurses become educated about their experiences in relation to promoting autonomy of adults with PMLD a point of mutual understanding will be achieved between all interested parties and the organisational structures they operate under will eventually be able to

challenge their own beliefs and values as well. Markwick &Parrish (2003, p.168) holds the view that,

> '*if the organisation believes it is offering people new opportunities and better ways of life involving choice and personal autonomy, the clients will see things the same way'*.

Adults with PMLD rely mostly on non-verbal communication behaviours to communicate such as facial expressions, gestures and eye contact and this raises particular challenges for those staff that includes LD nurses who have to rely on subjective inferences of the person's preferences and choices (Dobson et al, 2002; Hogg et al, 2001; Grove et al, 1999). Goode (1997) explores the concept of quality of life for people with profound disabilities in the nineties and noted a significant change in the staff's attitude from when he worked on the in the 1970s. By publishing a book on quality of life for people with profound disabilities in 1997, Goode acknowledges that it is a testament to how attitudes and values have moved on in the field of learning disabilities. Goode highlighted communication and cognitive impairments as major limitations to experiencing quality of life among people with profound disabilities and go on to claim that all data about an individual who cannot communicate or express themselves in formal language is inferential. Goode points out that it is not surprising that the subjective perception of quality of life adopted within this communicative-cognitive state will depend upon the individual's condition and experiences in life. Goode argues that evaluations of another's quality of life depend on the experiences and context of the persons designing and performing the assessment as much as it does upon those of the person being assessed. This means the assessor or observer uses their opinion about how the person with disabilities feels in order to assign 'a subjective state' based upon their observations or empathic response (Goode, 1997).

Evidence based practice (EBP) movement within LD nursing practice and the nursing profession as whole attracted new challenges to LD nurses in relation to promoting autonomy of adults with PMLD. These challenges have been attributed to the subjective, ambiguous nature of interpretations

based on inference (Phelvin, 2013; Moulster & Turnbull 2004; Dennis, 2002). Phelvin (2013, p.32) posed the this question,

> *'How are professionals to ensure that their clinical and psychosocial interventions with profoundly disabled service users, relying as they often do on subjective interpretations of non-verbal communication behaviours, have a sound, reliable and valid evidence base?'*

Goode (1997) notes that interpretations will always be inferential as the LD nurses' and adults with PMLD may not share experiences to assume reciprocity of perspectives. However, Goode (1997) withdraws from arguing that the only relevant factors in understanding how a person with such profound intellectual disability perceives their own quality of life are their own experiences and countenance. A particular kind of knowledge has been called for referred to as 'personal knowledge' (Phelvin, 2013). Phelvin argues that 'personal knowledge' underlies the processes of interaction, relationship and transaction between nurse and client. It included the specific 'gut-feelings' or intuitions that expert and experienced nurses may experience about particular clients (Phelvin, 2013). This information or personal knowledge cannot be gained by empirical observations of behaviours alone without the researcher interacting with the participants to explore their thoughts, perceptions/interpretations and feelings (Phelvin, 2013; Parahoo, 2006). This mode of knowledge is context dependent, non-discursive and non-generalizable, being specific to particular nurse–patient relationships (Phelvin, 2013). LD nurses, as one of front line professionals, play a crucial role in expanding options and opportunities presented to adults with PMLD to make or at least be involved in the process of making decisions and choices. Therefore exploring LD nurses' lived experience of promoting autonomy for this client group has a potential to contribute to EBP constitutive of the 'personal knowledge' or as described above, mode of knowledge that is context dependent. A qualitative approach to research and in particular a hermeneutic phenomenological research framework of inquiry will allow the researcher to analyse and understand how LD nurses understand, make meaning and interpret their experiences in relation to promoting autonomy for adults with PMLD. Hermeneutic phenomenology is an interpretive approach best suited for research that seeks to explore knowledge embedded in experience (Polit

and Beck, 2012; Moule and Goodman, 2009; Mackey, 2004). Potential therefore exist for this research's findings to contribute towards evidence based practice (EBP) through illumination and education on the experiences of LD Nurses in relation to promoting autonomy of adults with PMLD.

Johnson and Walmsley (2010) explored the concept of 'good life', equivalent to the concept of 'autonomous-self' in relation to people with learning disabilities through a re-examination of ideas from philosophy and social theory, and through personal life stories. Johnson and Walmsley provide an analysis and critique of current policies and underpinning ideologies in relation to people with intellectual disabilities and explore ways in which a good life may be made more attainable. Johnson and Walmsley cited approaches such as Integrated care pathways, life planning, PCP and health action planning. However, Their application within the population of adults with PMLD is challenged and threatened by a plethora of factors including complexities, subjectivity and multidimensional nature of the concept of autonomy, high level of dependency and multiplicity of needs, inadequate service provision, prejudice, discrimination and a history of low expectation. Difficulties in promoting autonomy of adults with PMLD are widely recognised throughout literature, in national policy and international human rights treaties warranting a need for research in the area to broaden nurses understanding of the processes of promoting autonomy that preserves and safeguards the rights, wishes, aspirations and civil liberties of this client group.

Although LD nurses attitudes and the general public's awareness of issues of civil liberties, rights and freedom people with learning disabilities continue to improve, recent evidence from several reports and inquiries highlight poor quality care, unacceptable restrictions, institutional abuse, neglect and discrimination against people with learning disabilities in public health services preventing them from exercising their rights to choice, independence and inclusion (RCN, 2010; CSAIHC, 2006). Findings made at Sutton and Merton Primary Care Trust includes care models based on the needs of the service rather than individuals, inappropriate use of restraint and lack of

service user involvement (Healthcare Commission, 2007). In another report, CSAIHC (2006) believed that staff training, policies and procedures, poor assessment, care planning and record keeping were the major causes of service failures at Cornwall Partnership NHS Trust. A series of recommendations were made including action on processes, training and identified responsibilities as well as a redesigning of the service reflecting a person-centred culture. Also mirroring these recommendations, the Healthcare Commission (2007) suggests the development of skills, experience and training opportunities for staff, provision of an advocacy service and most importantly that services should be based on the principles of person-centred care plans and health action plans. However, adults with PMLD are a diverse group and just like everyone else, they have their own history, personality and characteristics, values and opinions that need to be respected and are in constant change thereby challenging the Learning Disability nurse not only to be responsive and adaptive but also to be creative, perceptive and sensitive in their ways of working if they are to adequately meet the needs of this client group.

2.5. Conclusion

This literature review has highlighted a theme of constant change within LD nursing practice in response to developments in underlying philosophies of care, policy and socioeconomic context among many others. These changes are ongoing and continue to impact upon the experiences of LD nurses in undertaking their roles including promoting autonomy for adults with PMLD. Complexity and multiplicity of needs among adults with PMLD together with increased dependence on others in almost all aspects of their life makes this client group a unique one from people with a mild or moderate learning disability. Although improvements in service provision and quality of life have been noted, adults with PMLD remain marginalised and LD nursing literature generally focuses on the wider group of people with learning disabilities.

A need for a particular kind of knowledge ‘personal knowledge’ answering and informing ontological or practical concerns of LD nurses in relation to promoting autonomy of adults with

PMLD has been highlighted. However, a literature review conducted by the National Nursing Research Unit at King's College London (2007) showed that the majority of LD nursing research is descriptive or conceptual and only a minority of studies have evaluate direct nursing intervention or delivery of care by LD nurses in England. The gap is not new, Kearney and McKnight (1997) reviewed primary methods of assessing preferences and choices in persons with learning disabilities highlighted the need for a complete analysis of variables that mediated and lead to expression of preference, choice, and choice availability. These variables include client familiarity with staff members and tasks, staff member training, attitudes of staff members toward client choice-making. Saunders et al (2012) argues that it is necessary to study the details of a situation in-order to understand what is happening or even the reality occurring behind what is happening. Exploring and understanding LD nurses' lived experiences in relation to promoting autonomy of adults with PMLD has been highlighted as carrying the potential to drive change and improvements in care outcomes as the experiences are illuminated and understood.

LD nurses operate within organisational systems, policies and procedures of which when combined with attitudes, beliefs and experiences of themselves and that of others. These interact in ways that influence how LD nurses view, perceive and understand their experience of topic being explored. Understanding LD nurses lived experience of promoting autonomy of adults with PMLD will therefore elucidate or illuminate its meaningfulness from their perspective. Studying experience involve human explication and deals with interpreted reality with human meanings. This means the experience of promoting autonomy of adults with PMLD has a subjective meaning to the nurse and is dependent upon LD nurses' extended relationship with the nursing profession at its highest level, their personal and practical LD nursing knowledge, their attitude, their values and many other contextual aspects (Von Eckertsberg, 1998). This relationship is dynamic and experience continues to change and have evolving cumulative meaning, manifold, and shifting from aspect to aspect (Von Eckertsberg, 1998).

This literature review has also shown that promoting autonomy of adults with PMLD is a broad and complex phenomenon in learning disability nursing practice. As a social phenomenon and through human interactions its meaning and conceptualisation in nursing came to be understood from varying perspectives including legal, moral and ethical and professional. Promoting autonomy of adults with PMLD can be difficult and complex at times, highly ethical and politicised, demanding a high degree of individualistic approaches from nurses. Set against service provision based in independences, control, self-determination and individualisation, high level of dependency, complex and specific needs together with low level of functioning among the population of adults with PMLD as reinforced by difficulties in communicating presence significant challenges upon LD nurses regarding promoting autonomy of this client group. The literature review has indicated that there is no simple solution to the dilemmas experienced by LD nurses particularly where alternative ideological and philosophical basis of an action constitutive of promoting autonomy are in conflict and both equally valid in their own right. Also, LD nurses constitute both social agents and historical actors and meanings ascribed to their social actions such as promoting autonomy are in a continual process of constant change. This study seeks to explore LD nurses lived experiences in relation to promoting autonomy for adults with PMLD. The study question was formulated as:

> *What are the experiences of learning disability nurses regarding promoting autonomy for adults with profound and multiple learning disabilities in England?*

Research Methodology and Design

3.1. Introduction

To answer the research question and meet the study's aim and objectives, Heideggerian hermeneutic phenomenology was chosen to be the guiding framework of inquiry. A single method data collection strategy of in-depth interview was used.

The purpose of this chapter is to explain methodological assumptions and how particular philosophical underpinnings of hermeneutic phenomenology have been applied to the research methodology and design. The following will be described and explained; (1) how the research question has been addressed identifying ontological and epistemological stance taken by the researcher, (2) the chosen methodology and the overall framework of inquiry guiding the research process (3) study population, research setting and sampling approach used, (4) data collection method used, (5) data analysis process, (6) access to and ethical treatment of participants and (7) rigor, validity and credibility of methods used.

3.2. Methodological assumption

Denzin and Lincoln (1994) propose that all qualitative research requires consideration of three philosophical concepts of ontology, epistemology and methodology. They describe ontology as researcher's assumptions about nature of reality, epistemology as the researcher's belief about what social research should do and methodology as referring to the theoretical articulation of methods applied to the study. This study used hermeneutic phenomenology as its guiding framework of inquiry and therefore assumed an interpretivist ontological stance about nature of reality.

According Santankos (2005, p.316);

> *'interpretivists believe that knowledge is pluralistic and dominated by an inherent ephemeracy , fragmentation and ambiguity, depends on social and cultural conditions, discourses, belief systems, interpretive models, language systems and power systems'.*

Milburn et al (1995) explains the philosophical belief of interpretivism is the belief that our understanding of the social world or human behaviour is actively constructed by human beings and continues to evolve. To this effect, a constructivist epistemological stance to research has been adopted by the researcher regarding knowledge being sought about participants. A constructivist stance towards data means that social research seeks to understand the context in which the phenomena take place. This accounts for multiple realities and allows the researcher to better understand participants' descriptions and interpretation of their relevant experiences (Bryman, 2012; Milburn et al, 1995).

Epistemologically, multiple realities opposes positivist philosophy that takes a realistic stance towards data claiming that the nature of reality can be objective and that knowledge is invariant, universal and singular (Santankos, 2005). Contrasting positivist from intervpretivist, Bryman (2012) explains that positivists seek causality and predictability to test hypothesis while interpretivists on the other hand, argue that social research can produce only local, historically-contingent or mooded meaning and seeks explanation and understanding.

Promoting autonomy is a social phenomenon, understanding of which lends itself within interpretive qualitative research paradigm. Exploring LD nurses' lived experiences regarding promoting autonomy for adults with PMLD cannot be subjected to quantitative methodologies of indexing, measurements and quantifying as meanings and understandings of such experiences are embedded in the interrelationship of the person and context (Russell, 2004). As the literature review has revealed, autonomy is a complex phenomenon that has increased significance in subjectivity, meaning and values within learning disability nursing practice and the nursing profession as a whole. Its meaning will always be relational and an interpretivist ontological stance with a

constructivist epistemological approach to data entails that an interpretive qualitative research approach will be more appropriate in exploring participants' lived experiences.

3.3. Choosing the appropriate methodology

In this study, LD nurses' experiences of promoting autonomy were conceptualised as embodied and embedded in their everyday practices understanding of which is characterised in a particular historical context and influence of the individuals themselves (Marieke, 2013; Marotzki, 2004). This particular persuasion places increased emphasis on the way in which LD nurses attach their own individual meanings to their roles and the way contextual issues influence how they should be performed (Saunders et al, 2012). According to Guignonn (2012) understandings of an experience are constituted by value-laden meanings in need of interpretation in order to be properly understood. Guignonn explains that these meanings give us distinctive ways of understanding what it is to be a person in a particular world. However, Marieke (2013) claims that we experience that what stands out from an event or situation and that these disclosed parts of reality require explicit interpretation in order to appropriate their full meaning and significance. An interpretive phenomenological approach to research was therefore chosen to guide this study. Hermeneutic phenomenology, an interpretive approach to inquiry in social research that attends to the understanding of that what was experienced from a second person perspective will be used to explore LD nurses lived experiences of promoting autonomy of adults with PMLD (Marieke, 2013). A phenomenological inquiry does not fragment the experience and places emphasis on subjective perspective and there-being or situatedness of human beings in their life-worlds or natural worlds providing for an understanding of the person's reality and experience reciprocating the virtues of current nursing philosophy developed from individualised and personalised care (van De Zalm and Bergum, 2000; Benner, 1985; Omery, 1983). The process of enquiry produces findings that are well rooted in participants experiences and understanding of their world as well as being more ethically and experientially

sensitive to the virtues of nursing practice than other alternative quantitative methodologies (Adams and van Manen, 2008; Mackey, 2005; Van der Zalm and Bergum, 2000; Dinkel, 2005).

The theoretical basis and approaches to supporting people with learning disabilities are in a process of constant change (Kay, 2003; Markwick and Parrish, 2003). Cohen et al (2000) argue that phenomenological research framework is an important method with which to begin when studying a topic that has been studied but for which a fresh perspective is needed. Polit and Beck (2012) argues that phenomenological approach is particularly appropriate for studying topics that are fundamental to the life experiences of humans and that it is especially useful when a phenomenon being studied has been 'poorly' defined or conceptualised. McConnell-Henry et al (2009) acknowledge that phenomenology currently holds a privileged position within the discipline of nursing as an alternative to empirical science that allows for understanding nursing phenomena such as lived experience. Van der Zalm and Bergum (2000) views phenomenology as a method of enquiry that has made significant contribution to nursing knowledge particularly in descriptive and explanatory theory and that knowledge generated is relevant for moral and ethical action, contributes to knowing of the self and understanding necessary for sensitive and aesthetic interpretations and responses in nursing.

3.3.1. Phenomenology

Phenomenology has its origins in philosophy but has since been appropriated to provide a research method to the study of lived experiences (Grbich, 2007; 2003; Ferguson, 2001). Different phenomenologists take on different focuses and direction and two major branches exist, descriptive and interpretive. Edmund Husserl (1859-1938) is the accredited originator of the descriptive tradition of phenomenology and Heidegger (1889-1976) was the first phenomenologist to propose interpretive phenomenological approach to the study of lived experiences.

Husserl reasoned that understanding of human experiences is subjective and coined the term *life-world* referring to 'thereness' and claims this to be the source of all experiential qualities (Todres,

2005). Husserl wished to intuit and describe that what was given to consciousness by the *life-world* with the rigour and scientific objectivity (Dowling, 2007). To describe phenomenon of interest, Husserl proposed that researchers must be open to the participant's *world-view or life-world*, setting aside or suspending their pre-conceived ideas thoughts, memories and emotions to focus on the experiential context of conscious awareness and allow meanings to emerge (Grbich, 2007; Moustakas, 1994). He called this process *bracketing* and believed that through *bracketing* it is possible to gain insight into the common features or eidetic structures of any lived experience (Wojnar and Swanson, 2007; Lopez and Willis, 2004). For this reason, Husserl's phenomenology has been viewed as being too abstract, and reductionistic for focusing only on that which is experienced in the consciousness of the researcher, the experiential context of consciousness (Smith et al (2009).

Interpretive phenomenology is the other perspective championed by Heidegger (1889-1976) who was a student of Husserl and shared many commonalities with his phenomenology. In particular, the knowing and understanding of phenomena as perceived by the individuals who experience it in their *life-world*. Heidegger disagreed with Husserl's reductionistic core ideas of '*bracketing*' and stressed that interpreting and understanding and not just describing conscious manifestation of object of study must be the focus of phenomenological inquiry (Polit and Beck, 2012). Heidegger argued that Husserl's phenomenology was rather more philosophical, too theoretical and too abstract, prompting his proposition of a more ontological approach to understanding lived experiences (Smith et al, 2009). He proposed that meaning of human being's lived experience is inherently an interpretive process and argued that hermeneutics will facilitate this process of interpretation to reveal meaning of experience. Hermeneutics is used in theology to understand and interpret ancient texts but has since been used widely to understand artefacts, objects and life-texts such as narratives. Parahoo (2006) explains that Hermeneutic explores or refers to how socially and historically conditioned individuals interpret their world within a given context.

Combining phenomenology and hermeneutics, Heidegger called his approach hermeneutic phenomenology setting out a working methodology based on an ontological foundation of understanding that regards realities as existing in the form of multiple mental constructions that are experientially and socially based, local and specific to the person who holds them (Pernecky and Jamal, 2010; Grbich, 2007; Annells, 1997). Heidegger altered the application of phenomenology from describing core concepts and essences of lived experiences to seeking to answer the question of the meaning of being to understand the complex world of lived experience from the point of view of those who live it uncovering what fundamentally underlies the meaning of that experience (Smith et al, 2009; Parahoo, 2006; Makkreel, 1975). In doing so, it answers questions concerning meaning in the practical everyday life of people and provide an interpretation of the practical understanding of human actions and experiences (O'Brien, 2003). Jasper (1994) believes that hermeneutic phenomenological research embraces the complexities of caring and has the potential to address issues of concern and tensions felt by nurses in their everyday practice such as balancing continuity and change, between efficiency and effectiveness and between standardisation and customization. To explicate the lived experiences of LD nurses in promoting autonomy, Heideggerian hermeneutic phenomenological framework of inquiry was chosen to guide this study.

3.4. Research design

3.4.1. Study population

This is a cross-sectional study of LD nurses in England who work with adults with PMLD. LD nursing is a relatively small branch of the nursing profession in England constituting less than 15%, which is 511 of 27,133 nurses on the 2012 NMC register of registered nurses with a specialist practice qualification and up to 7% of a total of 306,346 qualified nurses in United Kingdom. Of these, only a very small proportion works with adults with PMLD. LD nurses are almost all based in the community working in group homes, client's own private home, day services and small short

stay assessment and treatment units. They play a central role in the lives of people with learning disabilities, particularly those with more complex care needs (RCN, 2010; DH, 2009; Mansell, 2006).

3.4.2. Study Setting

The study's participants were recruited from St Anne's community services, a not-for-profit learning disability provider of services to adults with a range of learning disabilities in the north of England. St Anne's community services is one of the largest service providers in England and the five services from which participants were sampled from are accessed by over 200 adult clients with mild to profound learning disabilities. Three of the five services where participants were recruited from are nursing homes with the other two being respite services. Participants were also recruited from Leeds and York Partnership NHS Foundation Trust community based profound and multiple learning disability team.

3.4.3: Sampling approach and strategy

This study followed non-probability sampling approach using purposive sampling strategy. Non-probability sampling does not conform to rules of probability theory devised to ensure a sample is statistically representative of a study's population (Robson, 2011; Sarantakos, 2005). It is an approach mostly used in exploratory research and qualitative analysis and its use in nursing research has been attributed to its convenience and economy as well as its appeal in unstructured interview research (Parahoo, 2006).

Sarantakos (2005) identifies four non-probability sampling techniques: (1) a*ccidental sampling*: employs no systematic technique to selection of participants as the name suggests. Participants are recruited into a study for accidentally coming into contact with the researcher; (2) p*urposive sampling:* is whereby participants are carefully selected by the researcher because of their experience and unique contributions that they will make about phenomenon being studied

(Denscombe, 2010; O'Brien, 2003; Ritchie et al 2003). It has been used in studies that seek to explore a topic and require the uniqueness of participants' knowledge and expertise to develop an in-depth understanding of that topic; (3) q*uota sampling:* is an approach where the researcher sets a proportion (quota) of participants to be recruited from specific population groups such as education, marital status and ethnicity. The researcher usually makes the decisions after considering all significant dimensions of the population to ensure that they will be represented in the sample. It is a particularly useful approach when the sample is small and the researcher wants to guarantee that at least one case from each dimension of the population will be included in the final sample; and finally (4) s*nowball sampling:* the researchers chooses the first few participants using any other method and then ask them to recommend other people who meet the study's selection criterion. This continues until data saturation is achieved. It is a useful method when the target population is unknown or difficult to approach in any other way.

Each sampling technique has its own areas of strength and weaknesses for example in accidental sampling; the researcher is not concerned with matters such as representativeness, objectivity and validity (Sarantakos, 2005). Quota sampling on the other hand attempts to achieve characteristics of probability sampling by thriving for representativeness and can be particularly useful in market research and political study's where opinions of all elements of the electorate will offer a balanced poll opinion (Robson, 2011). However, sample selection using quota sampling can be highly biased due to lack of sampling control (Sarantakos, 2005).

This study is a small scale exploratory research that seeks to explore LD nurses' lived experiences of particular phenomenon, 'promoting autonomy'. Moreover, with the target study population of LD nurses being relatively easy to identify and access, purposive sampling strategy was chosen for this study. Participants were selected for meeting the following criteria; being registered LD nurse and having experienced or experiencing promoting autonomy of adults with PMLD who live in England. Being a qualitative study meant that there was no need for a comparison or control group,

rather participants who met the selection criteria and were able to describe their experiences constitute the sample. Their ability and willingness to want to share their experiences with the researcher was an important aspect as the depth and richness in their descriptions enhances the study's rigor (Jasper, 1994).

3.4.4. Sample size

Nine participants were recruited into the study. The sample was made up of LD nurses with two having just over one year's experience of working with adults with PMLD while one had three years, three had over twenty five years and final three had just over five years. An extensive description of the sample's demographics is offered under findings (chapter 4). The researcher considered the sample to be reasonably heterogeneous by representing a wide variety of perspectives about the phenomenon being studied

In comparing statistical research with qualitative research, Holloway and Wheeler (1996) argues that unlike statistical research which sets out to estimate the incidence of a phenomena and generalization of findings to the sampled population, the latter requires a different logic in which statistical representation nor scale are not key considerations. Rather, it is a combination of the characteristics of the sampled population and the constituencies of phenomenon being studied together with the various aspects of the study including study question, aims, objectives and guiding framework of inquiry that will determine sample size. In hermeneutic phenomenological research for example, context has increased significance and the aim of inquiry is to seek in-depth analysis of lived experiences and understanding of its meaning to those experiencing it. This involves detailed transcription and analysis of unstructured interviews which demand a phenomenal amount of time resources. In order that every experience can be examined in depth, sample sizes are usually small in hermeneutic phenomenological studies (Smith et al, 2009; Silverman, 2005; Ritchie et al, 2003; Holloway and Wheeler, 1996; Patton, 2002).

Expert advice on the number of participants required in qualitative studies varies from as low as three to as much as fifty. Polit and Beck (2012) argue that a sample of ten or fewer is typical of phenomenological studies as some phenomenological researchers do not only gather information from participants but also make effort to experience the phenomenon. A sample size of between three and six participants has been suggested by Smith and colleagues (2009) as a reasonable sample size for a Master's degree level research project. With this in consideration and factoring in the complexities and multidimensional nature of human social actions such as promoting autonomy of adults with PMLD and the researcher's experience, a sample size of between ten and twenty was predicted. However, there is no rule or right answer to the question of sample size in studies using in non-probability sampling (Saunders et al, 2012; Smith et al, 2009).

3.4.5: Data collection

Data were collected using Individual and face-to-face in-depth interviews that were audio recorded. Interviews are widely used in qualitative research but a phenomenological interview is a specific type of interview. Moustakas (1994) describes it as a data collection approach involving the reliving of experiences in order to obtain concrete or naive descriptions of an experience to provide textual basis for data analysis. Interviews allows the researcher to gain insight into the participant's opinions, feelings, emotions and experiences (Denscombe, 2010; Parahoo, 2006; Mason, 2002; Cohen et al, 2000). Mason (2002) asserts that talking to people interactively, asking questions, listening to their descriptions and articulations and analysis of the use of language is an epistemological position taken by phenomenological researchers to generate data based on interpretivist ontology. Benner (1994) argues that unstructured interviews are central to hermeneutic phenomenology because when people structure their own narrative accounts, they can tap into their more immediate experiences and are able to give more details and include concerns and considerations that shape their experience and perception of the experience. Data collected through in-depth interview was therefore considered appropriate for this study.

Participants were asked to describe their experiences in as much detail as they can before being asked probing questions for explanations and elaborations to arrive at the meanings and structure of their experience. Moustakas (1994) explains that these concrete or naïve descriptions of experience and the underlying dynamics that account for the experience provides a central meaning and the units that enables researchers to understand the substance and essence of the experience. It therefore follows that participant's perspectives on the phenomenon of interest should unfold as the participant views it and not as the researcher views it (Marshall and Rossman, 1999). The researcher achieved this by developing an interview protocol (appendix 5) using broad open-ended questions that follows a fluid and flexible structure to allow participant's perspective on the phenomenon of interest to take lead (Mason, 2002; Marshall and Rossman, 1999).

Mason (2002) believes that using broad open-ended questions in interviews and probes enables the researcher to follow up on participant's specific responses along lines which are relevant to them and their context and which the researcher could not have anticipated. This allows for novel findings and unexpected themes to emerge, particularly useful when little is known of the topic being studied (Polit and Beck, 2012). Mason (2002) acknowledges the significant amount of interviewing skills demanded by a phenomenological interview as the researcher not only has to respects dynamics of social interaction but also engage in the intellectual pursuits of the research. Mason (2002) suggests that the researcher will need to be flexible and sensitive to the specific dynamics of each interaction and that a relaxed and friendly relationship between the researcher and participant is essential in establishing a good rapport. The researcher engaged with participants in general conversations prior to the interview to make them feel relaxed and comfortable and as the interview progressed the discussion moved from a broad perspective to being more specific on the lead of participants. This was so participants don't feel pressurised or threatened by the interviewer. After the interview the researcher continues to engage in conversation with participants on general topics, inviting any further question that may have risen in the course of the interview.

All interviews were conducted in locations chosen by participant and meeting the requirements of the study including being fee from distractions, comfortable seating arrangements to facilitate productiveness of the interview and offering adequate privacy and confidentiality. Participants consented to the use of excerpts from their interview transcript to support and verify meaning units and themes in the final report of the research findings. Consideration was given to ensure that all information used does not reveal participant's identity. Pseudonyms and codes have been used instead of real names and personal data. However, Face-to-face interview meant that it was not possible to maintain anonymity at every stage of the research process (Speziale and Carpenter, 2011).

Information collected from participants was handled and processed in accordance with the Data Protection Act (1998). Access to the data was limited to the principal researcher and research supervisors only. Participants' confidentiality was maintained at all times during and after data collection was completed. However, participants were made aware that out of duty in law and where there are matters of or reasons to believe that someone may be at risk of harm, relevant and proportionate information will be shared with other responsible agencies. Participants were also made fully aware of how the information will be used, disseminated, and handled after the study was completed. Information and any data stored on computer are stored with password protection to prevent unauthorised access to the data. These will be deleted when it's no longer required for the purpose of the study and in accordance with relevant ethical codes of research. Computerised external data storage devices and print materials were stored under lock and key at all times.

3.4.6. Data analysis

In hermeneutic phenomenology, data analysis has been described as being both a dialectic and an iterative process of interrogating the participant's descriptions with the aim of preserving the uniqueness of each lived experience while allowing an understanding of its meaning to be derived (Berg, 2009; Grbich, 2007; Von Eckartsberg, 1998). The analysis process used in this study

followed a seven-stage interpretive framework phenomenological procedure described by Diecklemann, Allen and Tanner (1989) and was conducted by the researcher using NVivo 10, a computer based data management software.

The choice of data analysis method depends on a number of aspects including the researcher's skills and preferences together with the study's underlying philosophical framework of inquiry (Grove et al, 2013). Alternative approaches to data analysis that can be used by phenomenological researchers depend on whether they subscribe to Husserl's descriptive phenomenological tradition or to Heidegger's interpretive hermeneutic phenomenological idealism. Three main methods of analysis by Van Kaam (1966), Colaizzi (1978) and Giorgi's (1985) involves bracketing and follow Husserlian phenomenological approach. Diekelmann et al (1989), Van Manen (1984) and an approach described by Cohen et al (2000) all subscribe to Heideggerian hermeneutic phenomenology. Unlike both Diekelmann et al (1989) and Cohen et al. (2000), Van Manen (1984) does not propose a step-wise approach. To enhance authenticity of research findings, Roberts (2009) recommends that researchers must be able to illustrate their steps in the data analysis process, ensuring that findings are not based on personal opinion, but are grounded on all data collected and follow a rigorous, analytical, transparent process. Dieklemann et al (1989) describe an approach to data analysis that follows a step-wise approach, easy to follow and adequate for small scale studies like a Master's Degree research (Roberts, 2009). Diekelmann's approach was therefore selected for use in this study and it has been identified as a specific framework recommended for Heideggerian hermeneutic phenomenological data analysis (Murphy et al 2009; Draucker, 1999). Murphy et al (2009) describes Diekelman's and colleagues (1989) approach as concerned with the meanings that individuals make of their experiences and acknowledges that meanings are embedded within a particular historical and cultural context allowing both researchers and participants openness to different interpretations.

Although Diekelmann et al (1989) approach follows a series of steps, the analysis proceeds as dialectic, iterative and circular process represented by the metaphor of hermeneutic cycle. Hermeneutic circle involves an ongoing dialogue between the researcher and texts from interviews with participants, field notes and any other external sources. Hermeneutic circle is explained further under findings (chapter 4). Parts of the text is read and understood in relation to the whole data and vice versa. Cohen et al (2000) describe it as a move from protocol to explication and interpretation by means of reflection. According to Heidegger (1962), this process should be repeated in terms of all that the researcher can learn about the broader culture and context of the participant from any and all sources.

Interview transcripts were rewritten and language moderated into a coherent summary under naturally forming meaning categories derived directly from the text itself. This avoided being too reductionistic and losing the aesthetics 'essence' of participants' account of their experiences (Berg, 2009). The meaning categories were then subjected to a process of continuous examination and refinement with repeating and redundant ones dropped in a dialectic and iterative process as described by Diekelmann et al (1989) (appendix 7) to form themes. This approach to data analysis is a multilevel analysis that acknowledged meanings as embedded within a particular historical and cultural context, allowing both the researcher and participants' openness to make different interpretations (Murphy et al, 2009).

3.4.7. Trustworthiness

A study's trustworthiness has been described by Morgan (2004) as that what ensures qualitative research represents the truth. However, this is not always easy in a hermeneutic phenomenological research due to multiplicity of interpretations. Bradshaw et al (2007) argue that interpretation of the experience being studied in a hermeneutic phenomenological research is participant's own interpretations that are then co-interpreted with the researcher hence multiple realities. Therefore

truth will never be scientific fact and findings will always be inherently tentative and relative to the context of the research. Pernecky and Jamal (2010) elaborate that ‘‘Truth’’ in hermeneutic phenomenology is neither an objective endeavour nor something awaiting ‘‘verification’’ or ‘‘confirmation’’ through a set of methodical tools. They argue that epistemologically, hermeneutic phenomenology is open to many possible interpretations and understandings and that truth is an interpretive construct, and involves assessing the trustworthiness or credibility of the researcher's interpretation of the participant's lived experience. To enhance trustworthiness of the study the researchers pre-conceptions and experiences regarding the experience being investigated has been established, participants' interviews, which were unstructured and used open ended questions, were audio recorded and transcribed verbatim. A detailed account of the research process is given and emerging meaning categories and themes are illustrated with extracts from participants' interview transcriptions to show how they have been derived.

3.4.8. Ethics

3.4.8.1. Permissions

Ethical approval has been sought and obtained from the University of Huddersfield School Research and Ethics Panel (SREP) (Appendix 9) and the Research and Development offices of participating NHS Trusts (Appendix 10). In private and voluntary organisations, service managers approved the study (Appendix 11). The study's research activity does not constitute a regulated activity with children and or adults as defined in the Safeguarding Vulnerable Groups Act (2006), as amended (in particular by the Protection of Freedoms Act (2010) and no access to and processing of service users personal information was involved meaning that full and proportionate review by NHS Research and Ethics Council was not required. Only Letter of Access (Appendix 10) was required and these were obtained from participating NHS Research and Development office.

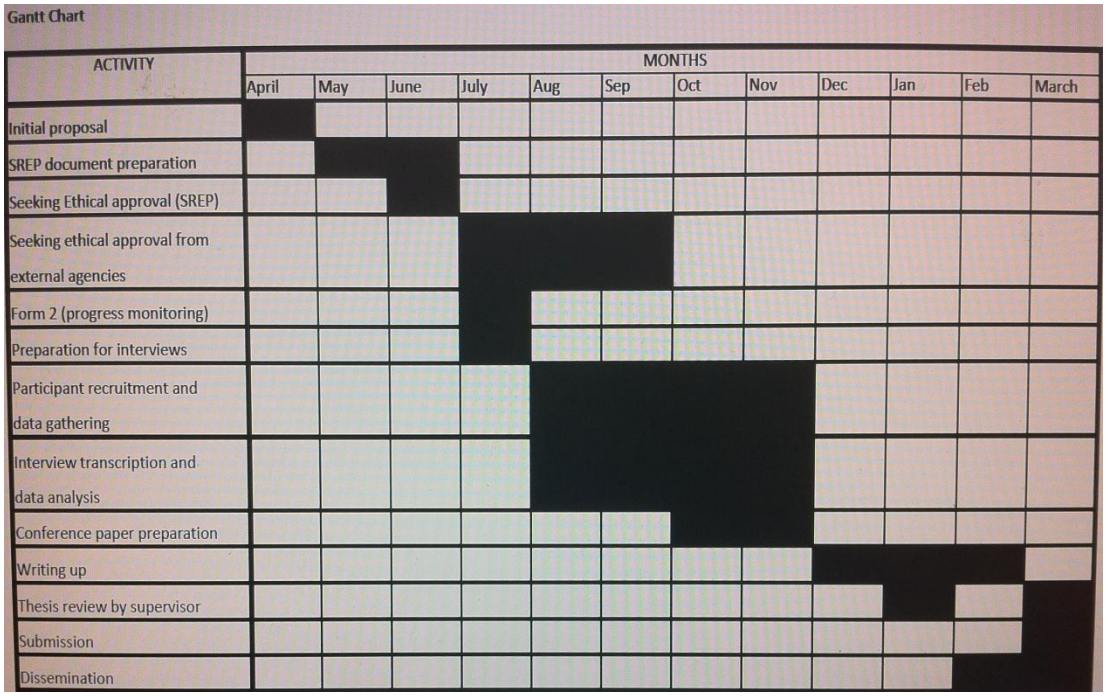
3.4.8.2. Consent

Participants were provided with recruitment literature in print form that included an invitation letter to take part in the study and detailed brief about the study detailing its aims and objectives, why they have been approached, their role in the study, how their personal information and data collected was going to be stored and handled, risk and benefits of taking part in the study. Details were also provided of who to contact if they had any questions or concerns regarding the study and would like further information. The study used a standard consent form which was also forwarded to all potential participants requesting for permission to take part in the study, have the interview audio recorded and to use interview excerpts in the study's final report. Participants were made aware of their right to withdraw at any point during the study without giving any reason. A written consent was obtained from all participants interviewed using a standardised form (Appendix 4).

3.5. Research schedule

This study was completed in one full academic year of 2013-2014. Participant recruitment and data collection took place over five months, from the month of August to December. Literature review was conducted during the data collection and analysis period following the study's guiding framework of inquiry. Using Hermeneutic phenomenology as a guiding framework of inquiry meant that the aim of the study was to discover meanings and interpretations of lived experiences of participants, a process that demands a great deal of creativity, time, critical thinking, and conceptual energy (Hoskins, 2004; Cohen et al, 2000). Steen and Roberts (2011) emphasise the need to be well planned and designed requiring the researcher to be prepared to incorporate all possible eventualities while ensuring that a systematic course of action is followed in conducting the research. Chart 1 below is the study's Gantt chart outlining the research process. Steen and Roberts believe that it is helpful to design a time plan including the phases, months and milestones that are proposed to assist the successful completion of the research.

Chart 1: Gantt chart



3.6. Summary

Informed by the research question, aims and objectives, this chapter has described and explain the ontology and epistemological stance to data taken by the researcher. A discussion on how research methodology was chosen follows. Multiple realities and an interpretivist ontological stance lend itself to interpretive qualitative research approaches. The logic of qualitative research to explore a social phenomenon from the perspective of understanding, meaning and interpretation by those experiencing it explains why Heideggerian hermeneutic phenomenological research framework was chosen to guide the study design. Human qualities (*Dasein*) and context or its situatedness (*being-in-the-world*) are key tenets of this approach and accessing these required close interaction between the researcher and participants in the form of an in-depth interview. The interview was audio recorded and transcribed verbatim to preserve its 'purposes' and aesthetics and to create textual basis for interpretive hermeneutic phenomenological analysis.

This chapter has also demonstrated the criteria of trustworthiness that was employed to enhance the study's rigor. Threats to the research methodology and design rigor were discussed and attending

to following Lincoln and Guba (1985) framework of four criteria credibility, conformability, dependability and transferability. Measures taken to ensure that the study complies with ethical guidelines were also described.

Findings

4.1. Introduction

This chapter presents the study's findings and the analysis of participants' interviews revealed multiple meanings to LD nurses' experience of promoting autonomy in adults with PMLD. Findings will be presented following the 'category' or 'theme and quote' method that involves the naming of each category and theme, describing that theme together with naming of any subthemes and meaning categories it consist of (Cohen et al, 2000). This is then followed by excerpts from interview transcripts that illustrate how the themes, subthemes and meaning categories were derived.

Data analysis followed an interpretive hermeneutic phenomenological approach described by Diekelmann et al (1989) (Appendix 7). Three main themes emerged pertaining to the LD nurses experience of promoting autonomy in adults with PMLD: (1) taking responsibility, (2) care delivery and (3) personhood. Each of these themes will be discussed in turn with excerpts from interview transcripts used to illustrate how they were derived. However, some excerpts do overlap and may not exclusively represent the theme they are illustrating nor does the researcher claim finality in interpretation. Readers are therefore being invited to further make their own understanding and interpretation in light of this study's findings.

4.2. Findings

A purposively selected sample of 9 LD nurses (n = 9) was recruited into the study from the north of England. A sample size of ten to twenty participants was originally predicted for use in study. Participants were recruited from Leeds and York Partnership NHS Foundation Trust and St Anne's Community Services which is a large registered charity and national provider of services to people

with learning disabilities. All participants who participated in the study work directly with adults with PMLD and Chart 2 shows participants' characteristics.

All participants consented to being interviewed, having the interview audio recorded and to the use of excerpts from the interview transcript in illustrating meaning categories and themes. Participants chose location of interviews and all nominated their place of work. Nine single-point unstructured and face-to face interviews were conducted in total between September 2013 and March 2014. All participants described their experiences regarding promoting autonomy for adults with PMLD. Each interview was audio recorded using a digital dictaphone and transcribed verbatim to create textual basis for data analysis. Appendix 8 is one of the interview transcript used in this study. Recording the interview allowed the researcher to capture a full record of the experience as described by the participants and to be freed from note taking during the interview to focus on what the participants are saying.

Chart 1 Participants' characteristics

Nature of services	Adult Day centre (Profound and Multiple Learning Disabilities) (n=1) Adult Complex needs and challenging behaviour nursing home (n=5) Adult respite services (n=3)
Experience	1-5 years (n=3) 5 – 10 years (n=3) 20 – 30 years (n=3)
Gender	Male (n=4) Female (n=5)
Post/grade	Registered Nurses on NMC Sub part 1: RNLD: Learning disabilities nurse, level 1 (NMC, 2010) (n=9)
organisations	Charitable organisation (n=8) NHS England (n=1)

The researcher conducted data analysis following dialectic and iterative seven- step interpretive hermeneutic phenomenological process described by Diekelmann et al (1989) and this involved the following stages;

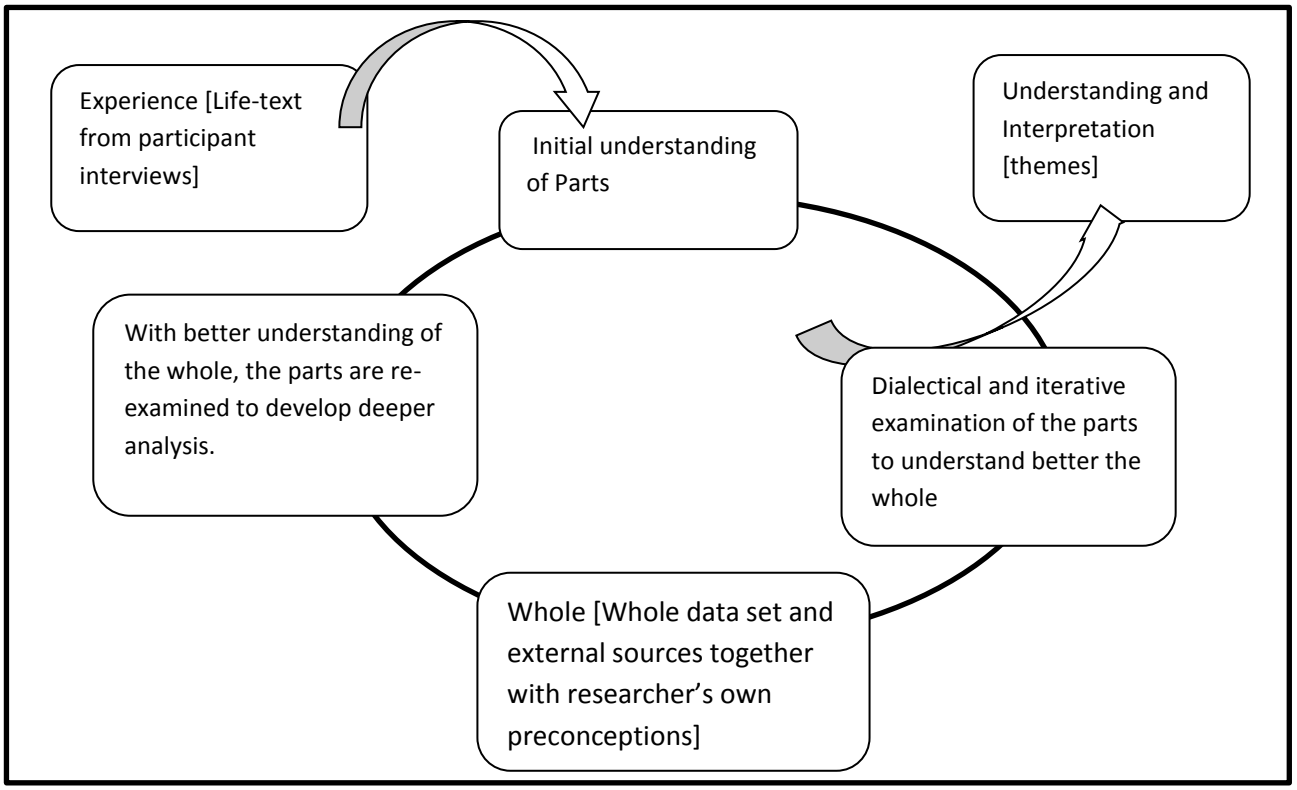
1. The researcher listened to the audio recording several times using the Dictaphone, before and during transcript and then after transcript to verify accuracy of the transcript. Each transcript was read and re-read more than once to acquire its global meaning.
2. Interview summaries were written up for each interview by reorganising the interview into possible meaningful units or categories and these were used later to form themes.
3. All meaning categories were then analysed and grouped into themes by being subjected to a process of questioning with reference to external sources and researcher's own pre-conceptions about the topic being studied. This and all the analytical processes that follow is represented by the metaphor of hermeneutic circle described below.
4. Emerging themes were further refined through interpretation, raising questions, recalling data from participants' interview transcripts, engaging with extant literature together with context of participants' experience and that of the interview.
5. Common themes or meanings were identified by comparing and contrasting texts and describing common meaning themes.
6. Excerpts from interview transcripts were identified to illustrate how the themes have been derived.
7. Discussing and verifying findings with others including research supervisors, participants and LD nurses meeting the definition of the study population.

Although described in terms of a step by step process, hermeneutic phenomenological data analysis is a dialectic and iterative process that involves moving from interview transcript to explication and interpretation by means of reflection (Cohen et al 2000; Von Eckartsberg, 1998). Dialogue is central feature of hermeneutics enquiry as the text is returned to time and time again to scrutinize a particular experience via its record in memory (Robson, 2011; Von Eckartsberg, 1998). Berg (2009) argues that a hermeneutic phenomenological approach to data analysis is able to capture the essence (that what makes a phenomenon what it is) by preserving the uniqueness of each lived experience of

the phenomenon while permitting an understanding its meaning. As a result context –sensitive themes are extracted from the data itself and through continuous examination and refinement in an iterative process that adds and acknowledges meanings as embedded within a particular historical and cultural context (Murphy et al, 2009). Findings are therefore more meaningful to the researcher, participants and readers alike.

According to Heidegger, the interpretive process is circular and involves moving back-and-forth between the whole and its parts and between the investigator's *fore-structure* of understanding or pre-understandings of topic being studied and what was learned through the investigation (Heidegger, 1962). This is represented by the metaphor of hermeneutic circle (Chart: 3).

Chart 3: Hermeneutic circle



Von Eckartsberg (1998) explains that 'hermeneutic circle' seems to palpate its object to speak its own story into our understanding while preserving the integrity, complexity and essential being of the phenomenon being investigated. Polit and Beck (2012) describes this as the researcher entering

into a dialogue with the text during which the researcher continually questions its meaning and becomes immersed into the life-text's network of meaning enrichment that contributes to new meanings to the ongoing dialogue. Hermeneutic circle requires the researcher to consider the meanings of the smallest units of data in terms of ever-increasing larger units of data and vice versa leading the researcher's analysis outside the context of the individual interview as well as the context of the individual participant (Cohen et al, 2000). However, hermeneutic work is open ended due to its continuously spiralling form of meaning and sense making throughout the analysis (Steeves and Kahn, 1995). Foster (1995) explains that hermeneutic circle operates on the premise that the understanding of texts evolves in a circle of understanding, analysing the meaning of individual texts and relating this to the totality of life worlds in which they originated, then reinterpreting the new separate texts anew. Eventually, the researcher will arrive at a full and enriched understanding of essential meanings of phenomenon being studied (Finlay, 2011).

Polit and Beck (2006) views the discovery of understanding, wisdom and multiple possibilities from the study of another world as the goal of hermeneutic studies. In that sense and in distinguishing hermeneutic phenomenological studies from descriptive phenomenology inquiry, Moule and Goodman (2009) argues that hermeneutic phenomenologist are therefore more likely to develop a 'fusion of horizons' or a mosaic picture than 'essences' as the presentation of research findings is less concerned with providing a specific conclusion presented by descriptive phenomenologists. Hermeneutic phenomenological studies offers a narrative that allows the reader to draw interpretations and meaning for their own use therefore allows for the understanding of experience in one's own natural setting or life-world making findings more meaningful. Mackey (2004) asserts that interpretive approaches such as hermeneutic phenomenology are more likely than the positivist approach to elucidate the depth and diversity of nursing knowledge.

All interviews were transcribed verbatim and produced a total of 20 500 words. Each transcript was imported wholly into NVivo, a computer based qualitative data analysis software that helps with

data management. A 'Category or theme and quote' method was used to present findings and this involves naming and describing of each theme within the context of the study with illustration of any meaning categories from which it was derived from (Cohen et al, 2000). Excerpts from interview transcripts were then used to illustrate emergent themes and meaning categories. Where an interview excerpt does not clearly articulate the theme or meaning category it illustrates, a tie in statement explaining why it is a good illustration of the theme or category is included. However, Cohen et al (2000) points out that there are no prescribed rules for deciding which form the presentation of findings should take.

To illustrate the analysis process an extract from participant P.1 interview read as follows:

Researcher
You work as a bank nurse
P.1
Yes in about 9 [services worked in as a locum LD nurse] homes so each week is completely different. So I get to see like a different level of disabilities, challenging, complex needs and the sort. I get to meet loads of new staff. Nurses and support assistance. So I get to see how people promote independence and autonomy for people with learning disabilities and I am quiet saddened to say that it does not always get promoted. Autonomy is not always the first thing for people to promote. So the majority [of nurses and support assistance] do not. They don't promote independence on the simplest of decisions like what they want to wear, what sort of foods they want to it for breakfast or the dinner, would they like a coffee or a tea, would they like sugar. You know, just those little decisions
Researcher
Yes. Those are decisions at basic level.
P.1
Yes. I don't always see that. I see people just doing it, not asking them. You know. Would you like a cup of tea or cold drink? That's about autonomy isn't it? You know. Making sure they have their own, they can make their own decisions if they have got the capacity to. You know, that's what I tend to see. But also I think professionals probably argue that the reason why they don't promote autonomy is because people with learning disabilities may make poor decisions.
Maybe like what clothes to wear, they might decide to wear a really short skirt when it's really freezing cold outside.(P.1)

This extract came from the beginning of interview 1 with participant P.1 who works as a locum LD nurse and therefore gets to move around different services. The highlighted phrases were identified as significant to the description of LD nurses experiences of promoting autonomy for adults with PMLD. From this extract there is an acknowledgement of uniqueness of each individual client (line 5), that the concept of autonomy being synonymous that of independence (line 8), of the felt sense resulting from observations of current practices reflecting that autonomy of adults with PMLD is not always a priority (line 9-11), of the attitude of other members of LD nursing team (line 10 – 15 and line 24-25), non-involvement of adults with PMLD even on the simplest of decisions (line 12-15). Reference was also made to issues of capacity (line 21-22 and line 24-25). As described above the highlighted statements constituted contributed to categories that emerged from this interview alone before being subjected to further questioning, analysis and comparison with the whole data set and other external sources. For example, in describing supported decision making system for people with learning disabilities who communicate unconventionally through simple smiles and gestures and body language, Devi (2013) notes that whether a person communicates unconventionally or not, their desires should not be ignored. Devi advocates that people involved in their support must together to understand a person's desires and choices and then provide the means for that person to exercise his or her legal capacity to live a chosen life. Other participants expressed similar views in ways unique to their experiences contributing to the significance of knowing the adult with PMLD as a unique individual. The theme of 'Personhood' emerged as a result. For example another participant P.9 expressed that they (the LD nursing team) have worked with the same group of clients for many years and felt that they know them well to make a better inference of their preferences about where they want to live following proposed closure of their current service;

> *'We have had to fight for some people to either come back with us or access other services. We have had to advocate for them even though it may be a long way for them to travel, their*

needs won't be best met in their local services. Only if they could voice their own. I think we know them well enough to know what they would prefer'. (P.9)

Following the same approach, two other themes emerged from the analysis, 'taking responsibility' and 'Care delivery' pertaining LD nurses' experiences of promoting autonomy for adults with PMLD.

4.2.1. Theme 1: Taking responsibility

The theme of 'taking responsibility' refers to a feeling of being proud to be an LD nurse. This theme constituted of LD nurses beliefs, values and their perspective of the concept of autonomy in relation to adults with PMLD. Heidegger's account of existential nature of being *(Dasein*) will be used to explicate this theme of 'taking responsibility'. In particular, the researcher will explore concepts of authenticity and inauthenticity and thrownness, both of which are constitutive of *Dasein.*

4.2.1.1. authenticity and inauthenticity

Heidegger proposed that human existence is constituted by value-laden meanings in need of interpretation to be properly understood and that a human being is characterised as a story or an event opening up to or owned by that what is there (Dylan, 2005). Authenticity is the human capacity to assess her primary desires in the light of higher or secondary-order motivations concerning what sort of the person she wants to be (Dylan, 2005). Guignon (2012) explains that these understandings give us distinctive ways of understanding what it is to be a person. Inauthenticity is an alternative way of being proposed by Heidegger constituted by cutting oneself off from engagement with *Being* because this way frightens or upsets or threatens or disturbs views and values and attitudes and assumptions that one holds regarding how they wish to engage with *Being* and what that engagement may mean. Inauthentic existence allows Being to disown any sense of being owned. Dylan also notes that as inauthentic beings, we interpret ourselves as reactive victims to experience.

Existing authentically and inauthentically shift and is impermanent with no better option to strive for. Rather, both authenticity and inauthenticity must be taken as '*human givens'* of existences upon which to base our meanings and interpretations of our experiences in the world. Dylan pointed out that authenticity and inauthenticity terms are only intended to offer description rather than prescribe ways of being. Participants in this study described different 'human givens of their existences' such as societies' attitudes towards people with learning disabilities, policy agenda and directives, nurse education, implications of evidence-based-practice and organisational procedures and priorities. One participant said;

> *'I have worked with a few people with autism that the way you would naturally see an inclusion in societies. We go here we go there we go shopping. To some people that would be an idea of their worst nightmare. And I think you can kind of blank it all and say we will just take everybody out but that's what the society tells what you should do. Instead you should want to do what the person wants to.' (P.2)*

Participant P.2 describes how one would naturally view inclusion or make meaning of their experiences when s/he takes clients out shopping. Participant P.2 goes on to suggest alternative way of perceiving the same experience that adopts an empathetic approach in seeking meaning from the perspective of the client. Interestingly and consistent with the concepts of aunthenticity and inauthenticity self-actualisation pursuits and assertion of autonomous-self is not what we (LD nurses as *Beings*) strive to achieve (Dylan, 2005). Instead we seek to exist as both aunthentic and inauthentic *Being*s. In other words being-with the 'human *givens'*. Dowson (2000) highlights the implications of these 'human givens' and states that that service agency staff including LD nurses believe that their ability to improve the lives of service users is limited by public attitudes. Dowson goes on to identify Government expenditures on welfare as a reflection of the priorities and perceptions of its electorate. Dowson argues that in the process of performing its services, LD services supports a public perception of service user which justifies the actions of those services.

Participants also related multiple difficulties in their experiences and at conceptual level one participant said;

> *'So autonomy I think its quiet hard, it's an alien concept. You would hope that everybody would strive to give as much autonomy to that person as much as they could. In terms of their understanding, receiving information and retaining information and making decision based on those facts but still I find it very difficult. Say for example there is one person that we work with, the only thing that she communicates with and I suppose its communication really. All she does is she puts her head forward. A few years ago she did used to grimace and turn her head away when she was eating and that was another physical response she could do. Another physical response when her feet were hurting, she would draw her legs up to the body but they are all physical responses. So it's very difficult to determine that person's level of understanding although we would always speak with somebody as if they are understanding. We always speak to somebody what we are doing and why we are doing it but for that person to have any control of that it is very difficult'. (P.9)*

At operational level and as an ethical concern, participants expressed difficulties in knowing how much autonomy to allow while ensuring the safety the clients. This was clearly articulated by another participant;

> *'All learning disability nurses knew what they should be doing but how much autonomy do you actually give and how much could you allow to have with safety. And its always been, in my view, a very grey area. Even though at times now, in 30 years I have been working huge changes have occurred. There has been lots of changes. People have always been in favour of promoting as much autonomy as the residents can cope with but it's a very grey area. Even amongst a staff team as to what each individual is capable of doing themselves. So you can have different opinions. Its very difficult to get the same opinions of everybody. Some people will think loads of things are dangerous. You try and give as much choices as you can but how much do we give or put in, do we impose by the way we asked, what we are choosing, do we influence by the limit of choices, do we get by without responses when we think we are getting there.' (*P.4)

Participant P.4 experienced deinstitutionalisation when people with learning disabilities were relocated from long-stay hospitals wards to their families, private dwellings and small group homes based in the community. This Government led initiative was orchestrated based on the pretext of increased autonomy, control, inclusion and involvement (DH, 2001). Dunn et al (2007) argues that a service philosophy founded upon independence and self-determination is likely present with dilemmas in which the conflicting discourses of autonomy, protection and risk might lead to

restrictions in the range of choices made available. Markwick and Parrish (2003) illustrate the complexities of promoting choices and autonomy during deinstitutionalisation using three case studies. The authors identified the experience as a journey for both the service user and the carers. For the service user it's about learning to deal with exposure to choice and autonomy from an almost lifetime experience of institutionalisation while for the organisation it is a journey from the institutional paradigm into valuing the individual with a genuine determination to have a positive impact upon one's own quality of life.

Participants expected this difficulty as they identified disparity between nursing knowledge and lived experiences. Such difficulties as described by participant P4 were common across all interviews;

> *'Valuing people it helps to shape the way you work. I think Valuing People…… its not exactly a word of the law but what it was good at was that it also expresses the fact that you need to have choice, choice which could include inclusion. It proposed a quite common sense approach. In a fact that they understood that within certain aspects of learning disabilities choice and inclusion cannot be looked at in one hand. In certain times in challenging behaviour, you can have restriction put on when you work with people with challenging behaviour that you can't include people in society.' (P.3)*

Participants interviews also highlight that negative constructs of being profoundly disabled held by other health and social care professionals including families of adults with PMLD contribute to difficulties experienced. One participant said;

> '*professionals probably argue that the reason why they don't promote autonomy is because people with learning disabilities may make poor decisions.'(P.1).*

4.2.2.2. Thrownness

Authenticity and inauthenticity is impermanent, human beings have the capacity to engage with either way of being is a universal attribute. Life events, for example can cause a shift to our world view Dylan, 2005). Our choice to ascribe to either ways of being gives a particular meaning to our world view. However there exist conditions where *dasein* has no choice. Heidegger (1962) referred

to this condition as *throwness*, meaning thrown into the world (Dylan, 2005). The person is thrown into a particular body, a particular time, a particular culture or a particular set of prevailing socio-cultural attitudes and mores, stances and opinions. Mitchell (2004) argues that as a profession, nursing has continuity in terms of its organization and its identity although it has changed in terms of its skills, its location and its policies in response to the needs of the period. Mitchell believes that this is one of the reasons why learning disability nursing in is constantly subjected to political examination. Therefore throwness is always situated in a structure or set of thrown condition. Within this throwness, Dasein can choose its meaning and through it express his way of being-with throwness:

Dylan concludes by stating that what inevitably remains for Being's existence within thrownness is to choose its meaning and through it express their way of being-with thrownness. Dylan adds that the construed meaning is not always, nor even often, reflective of differing options as to what an event might mean. Instead the given conditions of being's existence may well impose a non-optional meaning to ascribe one's own experience of being. Throwness is another way of viewing authenticity and inauthenticity and is not about throwing in the towel.

Acknowledging the thrownness of being an LD nurse, one participant's understanding of own experience was that all LD nurses can do is make a shadow of the past better;

> *'it is an area that needs to be always looked on because its important. People with learning disabilities I think they still do live in the shadows, but I think that's just going to be the way societies is going to be. But I think we can kind of make the shadows the best that we can. It is going to be a slow change. If I look at the attitude of people from when I was young to where I am now, I am [No. of years] now. When I was younger it was very derogatory, it was not even a shadow, there were behind the wall somewhere. It was not anything like lets listen to people bla bla bla . it was just a case we don't want. Now it is more acceptable in main schools, people can now work at levels that allows them to be able to be in school. Kids are growing up with people with learning disabilities. It will effect an attitude change.' (P3)*

This suggests that there are areas that LD nurses cannot offer choice in all aspects of the lives of adults with PMLD. Participants have highlighted housing and finance as two key areas where adults with PMLD have little options for choice. Participant P.6 who works at a nursing home for adults with learning disabilities spoke passionately about being able to offer basic day to day choices and went on to say:

> *'but I tell you what, thing they do not get a lot of choices is probably where they actually live because we have got a new lady, we have got a spare bedroom and again we have got limited places, so people who live here right now they don't have a choice, whether she is coming or not …….. No choice there. If we need the bed filling. Hopefully she will fit in with everybody. If somebody turns round and say we don't like her. If we don't want her to stay then at that point it will be out of my hands. The senior management has to look into it ……. It's no longer a home for life anymore, sometimes if somebody cannot meet their needs or can meet their needs better, they get moved around. A few years ago, there used to be 5 bungalows on this site and they closed number 4. They took 4 men out of there and those men had no choice in that, they had to move. The organisation Place the other two in a bungalow here, the other two went to a different organisation. They have to move people around.' (P.6)*

Participant P.6 expressed that she felt awful but contents that the organisation needs to grow:

> *'I personally thought we were awful, but as an organisation we have got to be growing and developing, and the respite is a busy service, we needed the respite. so people had to move out of their home to make way, they could have built somewhere else.' (P.6)*

4.3 Theme 2: Care delivery

The theme of 'care deliver' Refers to the daily practice of LD nursing and to a great extent does overlap with the other two themes of 'taking responsibility and 'personhood' that emerged in this study. This theme was constituted by two meaning categories: (1) 'teamwork' and (2) 'hands tied down in the past now we are being underestimated'. All participants contributed to this theme and valued the incorporation of theory, policy within everyday learning disability nursing practice in promoting autonomy for adults with PMLD:

'It would be important for people to move forward and in some places things have moved forward. They use paperwork like the valuing people and the human rights.' (P.1)

After being asked for views on policy development within learning disability practice, participant P.3 said:

'it helps to shape the way you work. Valuing People came out just before I went out to do my training…….. It was not actually policy, its white paper, its not exactly a word of the law but what it was good at was that it also expresses the fact that you need to have choice, choice which could include inclusion. It proposed a quite common sense approach. In a fact that they understood that within certain aspects of learning disabilities choice and inclusion cannot be looked at in one hand. In certain times in challenging behaviour, you can have restriction put on when you work with people with challenging behaviour that you can't include people in society.' (P.3)

4.3.1. Teamwork

The meaning category of 'teamwork' refers to working together collaboratively and in partnership with the adult with PMLD, their family and all others involved in their support. Participants in this study values the input of others in promoting autonomy for this client group including their families and other professionals involved in their care. Participants described multidisciplinary team approaches, educating family members so that they become active contributors and best interest meetings in their contributions to this meaning category. One participant P.1 said;

'It is important that everybody gets on board and everybody looks at that paperwork and understands the importance of it.' (P.1)

This extract suggests an elevated importance of working together not only at operational level but also from shared conceptual understanding. However, not all participants held the same view and while referring to working collaboratively with families and the society at large one participant said, '*very few people now look out for them [adults with PMLD]*.' (P.3). Reduced interest towards adults with PMLD suggests that they continue being marginalised in today's society.

Attitude, knowledge and understanding of family members about the rights of an adult with PMLD were also highlighted as very significant in promoting autonomy for this client group. This was well articulated by participant P.9 who works at a day service:

> *'A number of people we are looking after live with family and often the family can be the decision maker for that person. Often, whether rightly or wrongly, whether we would agree or disagree. You can sometimes have strong family members with strong opinions about things and that can be obstructing to things like treatment. They may disagree that wheelchair is not right for the person even if the person has been to the wheelchair centre and the physiotherapist, and occupational therapist have approved it as the best for that person's postural support. Sometimes you might get a family member who might say I don't agree so the person is in the middle'. (P.9)*

Participants have related this to priorities set out by the Government as influenced by financial deficits being experienced at almost all levels of service provision. The need for an integrated approach to services for people with learning disability has been highlighted in literature (Doody et al, 2012).

4.3.2. Hands tied down in the past now we (LD nurses) are being underestimated

This meaning category was clearly articulated by one of the participants who said:

> *'The thinking has not changed. Everybody was aware of what the residents wanted. Everybody wanted to give them. But the reality is and the practicality was that you could not do it. So the perception people have got is that the people wouldn't do it, No, it was not that they wouldn't, they couldn't do it. But everybody realized that it will be much better to go into small homes in the community. (P.4)*

Three of the nine participants had over twenty years' experience in working with adults with PMLD and referred to two different time periods in their narratives, 'old days' and 'now' with the 'now' being characterised by small community based dwellings while 'old days' referring to time when care and support was delivered in large hospital, participants felt that promoting autonomy of adults with PMLD remains a struggle and that it is hard going.

Participant P.4 articulated the 'old days' as follows;

'When I started working, they were in a ward that was very restrictive, you were talking about amount of staffing, staff service user ratios. So obviously you could never do everything the way you wanted. When I first started for example, just things like their own clothes it was really difficulty to get residents have their own clothes simply because there was a laundry that was set to the hottest point possible, so if you sent ordinary descent clothes they will be ruined. They would last two washes in the laundry. So you had to buy clothes that were virtually indestructible clothes which by their nature were awful clothes they had to put on.

For example like the way you are dressed and I am dressed, people dress appropriately to their age and fashion is very important in young people but they were very limited to what they could buy. There was also a limited amount of money they had because they were classed as NHS patients. So you are talking of the equivalence of 14 pounds a week today's money and out of that we had to buy all the Christmas presents, all the clothes, birthday presents and other things. So it was difficult to get individual things for the residents. So there was the practical difficulties you couldn't always take them down to the shop. You were talking about three staff to eighteen people per ward. Staffing ratios were low, you could not get to the shops. Sometimes we managed to get them out, it's how long could they cope with the surroundings they were not familiar with. As the years have gone by, the hospitals are closed down and we have gone into small units. That means you could have much more. That was a massive change.' (P4)

Another participant, P.6 described nursing practice on the long-stay wards;

'Very much regimented, when they were bathed it was more of a conveyer belt type system, because obviously with 30 patients and 3 staff, you talking of 30 odd years ago'. (P.6)

Care and support of people with learning disability in the large hospital wards was inhuman, derogatory, people were stripped of their individuality, and they were objectified. Words and phrases such as conveyer belt, institutionalisation, run down facilities, laundry temperature set at 100 degrees Celsius, large under-staffed wards and living behind a wall were used symbolically by participants to typify what life was like in the hospitals during institutionalisation.

The relocation of people with learning disabilities from hospital into community based small group homes was perceived by all participants as having enhanced opportunities for LD nurses to promote and safeguard the autonomous decision making capacities of adults with PMLD. Participants used the term 'now' in describing their current experiences and being in the community was viewed as important to LD nurses practice particularly the involvement of client's families and therapeutic homely environments;

'It was a better environment for relatives to come and visit. They were much more a part of the home. They were part of the outside when they come to the hospital, you would put them in a side room ……. The residents used to get frustrated in the wards and their behaviour starts to get worse. Everybody has seen that when they came out into the small group homes, the behaviours has improved massively because you got consistence of who looks after them, you got consistence of who they are living with you have a lot of space and a lot more autonomy within the home. But they also have got their own personal aims, bedrooms, personal effects, if they like TV or music they could have either of those. Everything is tailored to the individual need. ……. It is a massive change but it is for the better.' (P.4)

'They have got a much better quality of life now ……. our clients in the morning they get up when they want to get up , we knock on the doors, they didn't get that on the ward, we knock on the doors, we ask them do you want to get up. some don't and if they want leaving, we leave them longer. when we get them up then we ask, do you want a bath or shower, what sort of clothes do you want wear, what colour, what do you want for your breakfast? again giving medication, this is your medication, do you want to take it and as far as activities are concerned, do you want to do these activities, do you want to go out. Some don't want to go out, some do want to go out.' (P.6)

These two extracts illustrate how participants felt about changes to their experiences regarding promoting autonomy for adults with PMLD owing to a better environment.

All participants also expressed the view that philosophy and ideology underlying LD nursing has had a significant impact upon the quality of life of adults with PMLD as they are increasingly being afforded more opportunities to make decisions autonomously. Boyle (2007) asserts that the closure of large institutions and move of people with learning disability into independent living was seen as a fundamental ideology that will afford this client group autonomy and self-determination (Boyle, 2007). A study by Salmon et al, (2013) that explored the reflections and perspectives of staff who had experienced the change from institutional care to person-centred care. five of the seven participants' professional background was nursing and the changes from working in a long-stay hospital setting to working in a home for people with learning disabilities were perceived as having resulted in a more relaxed work environment that allowed staff to spend more time and offer more choices to residents than they could when they worked in hospital settings. Salmon et al (2013) found that this had the impact of encouraging them to work harder and freeing up their time to facilitate forming relationships with residents in the homes. One participant in the current study felt

that she has to work harder and fight for securing autonomy of clients under her care to be able to choose where to live as the service was closing down and relocating to a new facility over five miles away:

4.4. Theme 3: Personhood

The theme of 'Personhood' refers to knowing the person as a unique individual with own values, beliefs, personality. Personhood is a common theme across all interviews and participants valued knowing the person as a way of accessing the clients' preferences and choice. Adults with profound and multiple learning disabilities are not able to directly communicate a choice and this raises particular challenges for the RNLD (Phelvin, 2013; Ware, 2004). Participants valued their relationship with clients and knowledge of their client's behaviours, personality as access to knowing what the individual's choices and preferences are;

> *'We made a person centred plan for him in such a way that we discovered his likes and dislikes gradually, it was a very slow process but we eventually discovered what he liked and did not like and through encouraging him to do the things he liked. So basically it was like a reward approach for him that worked out at the end. For example, we would reward good behaviour with something that he likes and he would work towards that and it worked fantastic for him to the extent that we started noticing some prolonged periods of settled behaviours ……. he like going out to a game park. So it was like he will work towards that visit and you would see a period of prolonged settled behaviour that has not been seen before until he manages to go out and enjoy his hobby of seeing animals.' (P.7)*

> *'I suppose with someone with profound learning disabilities it can be a challenge to get in line with what you would perceive as full on autonomy for somebody that is severely disabled. Because obviously there is varying degree of independence within learning disabilities depending on whether somebody is profoundly disabled or not or somebody's physical disability. I suppose understanding that person's rights and understanding how that person feels and getting to know that person and kind of bringing that person's personal autonomy through in the relationship you have with them in your job and understanding what they want in life. Its getting to know how that person communicates. ……. likes and dislikes things like that. It kind of brings through somebody's opinions through. They react to certain questions and experiences they are having. ……. Seeing*

beyond the learning disability and profoundness of it. Seeing the personality behind that is always the best thing.' (P.3)

These interview excerpts illustrate how knowing client's personality revealed unforeseen dispositions that would otherwise have been taken for granted. Participants described different other ways of knowing the person including assessment and care planning, person's history, person-centred working, taking account of their likes and dislikes, intuition, experience and utilizing the family and other members of the health and social care team. Participant P.3 felt that promoting autonomy of adults with PMLD can sometimes get washed under the carpet and said;

'When somebody has a learning disability, it can have a massive impact. From my experience it can get washed under the carpet because somebody can't be able to physically walk towards what they want. For example somebody uses a wheelchair to access somewhere but can't push themselves. You know they are relying on that member of staff or that carer to understand their wishes and beliefs and what they want to get out of a certain situation. A great way to do. It is knowing the person. The learning disability nurse should not always be part of your job, the personality is the main thing for me and that will help somebody make their own choices. Help you help the situation improve their access to their rights really to be more autonomously and get what they ultiP3ely get what they want out of life.' (P.3).

Participant P.1 also expressed that it does not always get prioritised and felt saddened about it;

'I get to see how people promote independence and autonomy for people with learning disabilities and I am quiet saddened to say that it does not always get promoted. Autonomy is not always the first thing for people to promote. So the majority [of nurses and support assistance] do not. They don't promote independence on the simplest of decisions like what they want to wear, what sort of foods they want to it for breakfast or the dinner, would they like a coffee or a tea, would they like sugar. You know, just those little decisions.' (P.1)

Discussion

5.1. Discussion

Promoting autonomy of adults with PMLD constitutes a fundamental element of learning disability nursing and the consequential difficulties and challenges experienced by learning disability nurses are well documented (Long & Kavarian, 2008; Ware, 2004; Markwick and Parrish, 2003). These have been attributed to difficulties in conceptualisation and operationalization of the concept of autonomy in adults with PMLD due to multiplicity and complexity of needs, dependence on others for almost all aspects of their lives and communication impairment (Petry et al, 2004; Mansell, 2006; Meininger, 2001; Davies et al, 1997; Ray, 1994; Luckasson, 1992). However, there is very little research exploring lived experiences of LD nurses in promoting autonomy of this client group (Moulster and Turnbull 2004; NNRU, 2007; Mitchell, 2004). The gap is not new, a literature review by Kearney and McKnight (1997) highlighted the need for a complete analysis of variables that mediated and lead to expression of preference, choice, and choice availability including client familiarity with staff members and tasks, staff member training, attitudes of staff members toward client choice-making. This study has explored LD nurses' lived experiences of promoting autonomy in adults with PMLD who live in England. Three main themes emerged from this study pertaining to this experience; (1) 'taking responsibility', (2) 'care delivery) and (3) Personhood. Heidegger's account of existential nature of being human was used to illustrate the theme of 'taking responsibility' and the researcher used particular concepts of 'authenticity and inauthenticity' as well as 'thrownness' as meaning categories. The theme of 'care delivery' was illustrated by two meaning categories of 'teamwork' and 'hands tied down in the past now we are being underestimated'. From the findings of this study, the researcher concludes that meaning and interpretations of LD nurses' lived experience in promoting autonomy of adults with PMLD is perspectival and depends on a number of aspects. These include prevailing societal attitudes and

values towards adults with learning disabilities, socio-economic and political landscape, national policy guidance and directives, definitions and conceptions of disability and what autonomy means, individual LD nurses' own values, knowledge and attitude as well as the virtues and integrity of LD nursing profession itself. A constant change in theoretical basis of LD nursing practice is acknowledged throughout literature (Brewster and Ramcharan, 2010; Raghavan and Patel 2008; Markwick and Parrish, 2003). For example the publication of the White Paper Better services for the mentally handicapped (1971) saw a fundamental shift in philosophy for people living in institutions into small community based establishments.

The theme of 'Taking responsibility' referred to taking pride and owning up to the virtues and tradition of learning disability nursing. Taking responsibility relates to all three dimensions of LD nursing, its past, the current and its future. Within this study, participants have acknowledged and described their experiences in the past, the continued influence of society's values and attitudes towards adults with PMLD and the impact of policy change upon LD nursing practice. Participants have used these experiences to map the future of LD nursing practice in relation to promoting autonomy of this client group. Participants have related meanings of their experiences to the history of LD nursing practice particularly institutionalised care and to other contextual issues that includes personal experiences, socio-political, and economic climate. Participants in this study felt that they are promoting autonomy for adults with PMLD but this is limited to basic day to day matters. A range of limiters have been described including the safety of the individual, complexity of needs, theory and lived experience gap, organisational priorities and national agenda. Breaking the promise of home for life based on the pretext of business growth, unmet needs of the person or capacity to meet needs of the person was highlighted as a major violation of the virtues of community living 'ordinary life' for adults with PMLD. Participant P.6 expressed this view regarding a new client who was looking to move in for end of life care and said;

> '*Then again the new lady that we are getting, I knew her from [year] and you know she has been here and there and around. It is no longer a home for life anymore, sometimes if*

somebody cannot meet their needs or can meet their needs better, they get moved around'. (P.6)

The philosophy of 'ordinary life', driven primarily by prospects of empowerment and independence, forced a change in social discourse and political landscape towards people with learning disabilities resulting in the closure of large institutions in favour of community based care models (Shepherd, 1998). According to Dunn et al (2007) This 'ordinary life' philosophy has been embraced by government policy in the UK in developing services, and has informed the White Papers, Valuing People (DH, 2001) which has been built around the principles of rights, independence, choice and inclusion.

Participants within this study also highlighted the dilemma of how much autonomy to allow whilst ensuring safety of the individual. Participants generally found that promoting autonomy of adults with PMLD is a 'grey area' and not always a clear cut black and white issue. Participants described autonomy as an 'alien concept' in relation to adults with PMLD highlighting the difficulties in balancing professional duty of care against the safety of the individual. In other words the difficulty of determining what to give priority, protection or the person's right to self-determination. Participants also described the difficulties that arise when an intervention perceived to have an outcome of promoting autonomy of a client sounds unethical. For example use of restrictions, disregarding expressed preference, guiding client's decisions and proceeding without getting a response based on the pretext of ethical theories such as consequentialism, that an action is good if the outcome is favourable to all parties concerned. This is consistent with findings from a study by Blackmore (2001) which showed that nurses use the term 'advocacy' to describe a variety of activities that are underpinned by the opposing ethical principles of autonomy and paternalism. Advocacy is recognized as one of the key roles of LD nurses in promoting autonomy for adults with PMLD (O'Brian and Kumuravelu, 2008). O'Brian and Kumuravelu highlight the importance of this role for people with learning disabilities who may not always be able to self-represent in the process of deciding requiring support. In another study and using a case study approach, Crichton

(1998) illustrates how misinterpretation of, and conflicting philosophy of care can result in parentalistic over-control being replaced by under-control.

Heidegger's account of nature of being aunthenticity/inauthenticity and thrownness was used to illustrate the theme of 'taking responsibility'. From these accounts, meanings of experience of *being* are conceptualised as being always value laden with their significances derived from relevant socio-historical context (Guignon, 2012). Participants within this study have interpreted the meanings of their experiences not only within professional contexts but have related this to the wider context of LD nursing practice. This is consistent with the concept of Social-professional-personal integrity described by Guignon to mean standing apart from and being part of the personal motives and desires and the social-professional horizons of experience. As a participant or agency in the social context, the LD nurses are indebted to the historical tradition of the community they are part of (the social-professional dimension) and this has a limiting effect upon one's possibilities of self-interpretation and self-evaluation (Guignon, 2012). This takes two perspectives, first the LD nurse can be a respondent answerable (accountable professional) for what s/he did and this has been embraced within the professional codes of conduct and policy documents (Guignon, 2012). Secondly the LD nurse can be equipped to be an effective moral agent in facing situations demanding decisions. Therefore, the stance that LD nurses take towards adults with PMLD is important in the execution of their professional virtues and values.

Society's perception and constructs of disability have and to a great extent influenced the way in which care and support for people with learning disabilities is provided. For example, prevailing eugenic ideologies of the 50s based on the belief that people of low intelligence will contaminate the national genotype if they were allowed to procreate unhindered. People with learning disability were housed in isolated institutions where control, paternalism and protection were dominant values (Crichton, 1998). Participants within this study felt that approaches and underlying philosophies of

care service delivery for people with learning disabilities have moved on for the better. However, the way of being authenticity and inauthenticity remain impermanent and what is important to understand is that the same or similar conditions can generate a shift from authenticity to inauthenticity and vice versa (Dylan, 2005). Heidegger makes it clear that there is no better way of existence to strive towards in that efforts for authenticity can be seen as an expression of one's own inauthentic stance towards their way of being that is there for them. Dylan points out that an illustration of being or one's world view in terms of authenticity and inauthenticity seems to have little to do with personal empowerment of self-actualisation, and professional autonomy of LD nursing profession.

The theme of '*care delivery'* emerged within this study referring to promoting autonomy of adults with PMLD as everyday learning disability nursing practice. Participants within this study expressed that promoting autonomy of adults with PMLD is an embedded and entrenched everyday practice and perceive it as that what constitute being an LD nurse. However, common to all participants was the expressed view that promoting autonomy of adults with PMLD is only an ideology and accept with a feeling of guilt that it may not always happen. Nursing has a strong traditional base and with this tradition comes a sedimented view of phenomena such promoting autonomy and Burns and Grove (2009) argue that newly qualified nurses are introduced to these sedimented views early in their nursing experiences. According to Marotzki (2004), the task of humanities consist of understanding, socially interrelated individual 'life units' and refers to the individual person as their forms of expression, their words and actions. These individuals however, are not understood as isolated atomised subjects but rather as mediated by socialization. This means that they are embedded in social units such as families, groups and society while on the other hand they are characterised in a particular historical context and the individuals themselves influence these units hence the multiplicity of understanding and meaning. Dylan (2005) concludes by stating

that service providers needs to acknowledge that the given conditions of one's body, time and culture impose a non-optional meaning to which he can ascribe his experience of being. Luckasson (1992) points out that at a local level and within organisational policies and procedures, this is reflected in the dynamism and variations of how the concept of autonomy has been operationalized in day to day nursing practices. Therefore, policy writing and operationalization of these policies into practice holds a crucial position towards how LD nurses make sense of their experiences. The Parliamentary Committee for Human Rights proposes a Human Rights approach to issues affecting this client group and suggests that organisations and other service providers must take measures to ensure that the core principles and values of Human Rights are operationalized in their policies, procedures and day to day activities. Commenting on the development of less restrictive service delivery models post-war and in the 70s, Markwick and Parrish (2003) note that history has proved that to turn the tables it takes more than an input of resources in terms of finance and infrastructure but a substantial shift in social constructs of disability, attitudes, values and belief systems, power and control. Saunders et al (2012) argue that it is necessary to study the details of a situation in-order to understand what is happening or even the reality occurring behind what is happening.

Within this study participants valued working collaboratively with the adult with PMLD, their families and all others involved in their care in promoting their autonomous decision making capacity. During deinstitutionalisation, Kay et al (1995) describes the role of a learning disability nurse was as one of providing individualised care to people with learning disabilities and their families and collaborating with others to create alternatives to hospital care. Care and support of people with learning disability in the large and long-stay hospital wards was inhuman, derogatory, people were stripped of their individuality, they were objectified and in participants' interviews words and phrases such as 'conveyer belt', institutionalisation, 'run down facilities', 'laundry temperature set at 100 degrees Celsius', 'large understaffed wards' and 'behind the wall' were used symbolically to typify LD nursing practice at the time. Historically, people with disabilities including those on the profound or severe spectrum were institutionalized with segregated lifestyle,

curtain choices and autonomy (Markwick and Parrish). This was motivated by a number of factors including the Prevailing eugenic ideologies based on the belief that people of low intelligence will contaminate the national genotype led to people with learning disabilities being institutionalized (Markwick and Parrish 2003). The institutions were symbolic of societies assumptions at the time as people with learning disabilities were kept away from ordinary life (Dowson, 2010). Policies have also played a role in separating and isolating this client group took away choice by fostering dependence rather than interdependence. (Waker et al. 1995). Professional control characterised lives in the large institutions and opportunities to make decisions more autonomously were severely restricted (Brewster and Ramcharan, 2010; Shepherd, 1998).

Institutions have since been closed down and Moulster and Turnbull (2004) argues that the current purpose of nursing a person with learning disabilities is to work in partnership with the individual to improve his or her personal autonomy. Participants in this study highlighted the importance of working in a person centred way, consulting with the person with disabilities, their family and all those involved in their care to promote autonomy of adults with PMLD. This is consistent with findings from a study by Norman et al (1996) in which expert informants were asked to report on the relevance of nurse education in learning disability. Part of the study included exploring the current purpose of learning disability nursing with them. Most respondents identified promoting autonomy, supporting self-advocacy and assessing need as the main functions of the nurse.

Teaching family members to recognise their role in promoting autonomy of their disabled family member was also a common theme across all interviews. Raghavan and Patel (2008) points out that involves undertaking roles in mitigating the effects of disability, achieving optimum health, facilitating access to and encouraging involvement in local communities, increasing personal competence, maximising choice, and enhancing the contribution of others either formally or informally involved in supporting the individual. Participants within this study valued current approaches to working that involves the adult with PMLD, their family and others involved in there

are such as best-interest meetings and Person-Centred-Practice (PCP). PCP replaced through individual Personal Programme (IPP) that was based on the constructs of normalization. According to Markwick and Parrish (2003) normalization is about fitting people into what the society views as normal while PCP asserts autonomous decision making by the person with learning disabilities to gain more control over one own life in realisation of hopes, dreams and aspirations. Brewster and Ramcharan, (2010), argues that PCP seeks to acknowledge and recognise the individuals' unique identity, valuing whatever label they have been given because of their difference. PCP was therefore a completely different way of seeing and working with people with learning disabilities (Saunderson, 2000).

The theme of 'personhood' was common theme across all interviews referring to seeing beyond the disability, getting to know the person's values, beliefs, personality and most importantly as an equal human being. This was highly valued particularly when there is no is no verbal prompt. Participant P.9 said;

> '*People we work with are mostly non-verbal and in terms of giving power and responsibility and choice we would hope that as a carer we can think of these things from the carers perspective and from that person's point of view, to consider options I suppose for that person but its difficult to get sort of more in-depth communication'.* (P.9)

From knowing the person well, all participants contents that they can pick up on physical and emotional response and be able to make of inference of the person's preferences and choices. Participant P.9 added that;

> '*Because we normally work with people here Monday to Friday, people we have known for a very long time we obviously know the individual quite well and because of the complex learning disabilities, physical and health needs and if people do not know them that well and there is some inconsistences in staff at least we sort of know that person quiet well and can observe any changes from a physical point of view. We can pick up on that quiet easily. That is important because the person may not be able to verbalize or communicate. There may be subtle signs, the person may be sleeping more or not eating well or the behaviour has changed, so we can sort of pick up on those sort of cues from having known the person really well in comparison to those who don't work with the person that often, say a community nurse who may go on a visit. So we are quiet fortunate we have got that knowledge about that person then obviously we can pick up on things'. (P.9)*

Adults with profound and multiple learning disabilities are not able to directly communicate a choice and this raises particular challenges for the LD nurse (Phelvin, 2013; Ware, 2004). Participants valued their relationship with and their knowledge of the client's behaviours, personality as access to knowing what the individuals choices and preferences. Ware (2004) argues that in eliciting the views of people with profound and multiple learning disabilities, taking account of account of their likes, dislikes, strengths and needs allows those supporting them in making major life decisions about their future. LD nurses must therefore seek to broaden their knowledge of how the person communicates their choices and preferences. An unpublished study by Richardson sited by Leaning (2006) explored the use of a new approach called 'from the inside looking out' (FILO) designed to develop communication, interaction and emotional literacy skills with people with profound and multiple learning disabilities. The approach was run for eight weeks with five participants with profound and multiple learning disabilities in an adult learning disability day centre in London and its aims were to build relationships and enhance awareness of emotional variables. Data were collected by video recording and analysed using both qualitative and quantitative methods. It was found that a number of discreet observable behaviours related to interactive ability were positively changed across all participants. Richardson concluded that the study supports the employment of FILO and its principles in working with people with profound and multiple disabilities. Through the analysis of the changes in positive and negative behaviours, the results suggest that all five participants experienced a functional increase in their ability to relate to the facilitators.

Knowing the person as an individual and being responsive to individual and family characteristics'' is one of the seven key components of person-centred care as identified by Talerico (2003). However, Porter et al (2001) points out that it is important that the degree of inference involved in eliciting the person's likes and dislikes is acknowledged. One participant P.6 said, '*it's a mind game'* while describing own experiences of supporting a lady who is blind to make choices about how she wants to spend her time during the day;

'one of the lady I look after could sit up and cry screaming, and you have to ask what is the matter. you got to try and colt her around and checking her out. some time she come to you and sounds fed up, you ask what is the matter, she wants to out. but that time she wanted to go out. sometimes there is things going off and we can't take her out and then, as the day is gone but, we say hey we have booked this. this morning she was crying, saying I don't want to go and I have had to talk her into going but again she has since been fine. she is a somewhat apprehensive about going to places that she does not know or does not quite understand. I had to explain to her today that you enjoyed this the other day and that this is just going to be like that, you are going to be with your keyworker holding your hand. No one is going to leave you alone. so now she is gone. I would think if you had listened to what she had said initially you would have thought she don't want to go. sometimes she misses on going out because of the apprehension. her apprehension of going somewhere she don't quite understand where she was going so could cause her to say no I am not going. however, when she has gone she will enjoy it. sometimes you will have to, coach her into going. but if you had listened to what she had said she would have missed out. so there is no two days alike, no two clients are alike.' (P.6)

According to Sanderson (1995), the challenge for those supporting person with PMLD is to develop skills in recognising people's individual styles of communication, responding to them and offering as well as expanding opportunities to make meaningful choices. Participants experiences revealed the difficulties involved in eliciting the views of people with profound and multiple learning disabilities due to not able to directly communicate a choice. (Ware, 2004). Ware argues that given a skilled interpreter, the great majority of individuals with profound and multiple learning disabilities can express their choices and preferences. This was particularly important for adults with PMLD with impaired communication abilities.

Being able to interpret subtle behavioural or personality change was very important to all participants in this study and Ware (2004) believes that it has a real impact on their quality of life of people with profound and multiple learning disabilities. However, this demanded a set of skillset, resources such as teamwork and a strong personal commitment. Nurse educators will have a role in instilling the ideologies of promoting autonomy into the minds of student LD nurses as they come into the profession. Having the right attitude was identified by two participants in this student as important when it comes to promoting autonomy of adults with PMLD in light of the influence of society's attitude and values upon meanings LD nurses attach to their experiences.

Limitations, Conclusions and recommendations

6.1. Limitations and delimitations

Potential limitation of this study stems mainly from its theoretical framework and methodological approaches used (Burns and Groove, 2013). Hermeneutic phenomenology is not and does not prescribe a specific methodological framework of inquiry and this flexibility plays to its strength and weaknesses. Following a flexible exploratory design presents its own challenges in that it reduces controls to data collection threatening the validity and reliability of the research findings (brink and woo, 1998). Attride-Stirling (2007) points out that if qualitative research is to yield credible and meaningful results, it is imperative that the material under scrutiny is analysed in a methodical manner. In this study credibility was achieved by following an established approach to data analysis as described by Diekelmann et al (1989).

This was a small study involving 9 LD nurses and the small sample size has potential to limit credibility of findings (Patton, 1990). Bernard (2013) argues that credibility of findings is enhanced by the power of the methods sampling strategy. The use of non- probability sampling in this study contributes to internal validity as this is determined by the quality of participants used in the research and the degree to which a reader believes on conclusions about the people who were studied (Bernard, 2013). Paradoxically, another potential limitation of the study could come from sampling strategies used by the researcher. Phenomenological study is limited by its dependents and willingness to describe their experiences with depth and richness. This attracts the potential consequence of excluding the experiences of those who may not be able to articulate their experiences. Therefore findings from this study are subjective and highly contextualised referring specifically to the experiences of LD nurses who were interviewed (Phelvin, 2012). In describing categories and themes, Sjostrom and Dahlgren (2002) suggests the need for the researcher to show that chosen way of describing differences and similarities between categories is well supported by

the empirical material. Sjostrom and Dahlgren also advocates that the practice of providing excerpts from the interviews in the final research report to substantiate the relevance of the categories.

This study used single point interview lasting between thirty minutes to one hour. Longer times with participants and repeated or longitudinal interviews would have enhanced the richness and depth of findings by allowing exploration of changes to experiences. The researcher used unstructured interviews that allowed participants to explore their own experiences without being constrained by the structure of the interview. Broad open ended questions were used with probing questions.

The goal of interpretive phenomenology is increased understanding of the multiple interpretations of the meaning of human experience and data collected is very subjective. (Lopez and Willis 2004; Cohen et al 2000; Van der Zalm and Bergum 2000; Draucker 1999; Van Manen 1997; Annells 1996). This means findings are co-constituted by researcher and participants' interpretations and these are not final. As Lopez and Willis (2004, p. 730) point out, 'there is no one true meaning'. This notion of multiple truths could create challenges for readers of hermeneutic phenomenological research in deciding which study is more rigorous than another (Madison, 1988). Expressions of rigor help to distinguish among these diverse interpretations which one is better (Madison, 1988). Little (1999) points out that this may limit phenomenological research findings in terms of providing common recommendations for educational programmes and securing funding for further research, such approaches can serve to expand upon existing beliefs about the nature of contemporary nursing practice. Findings from this study support existing literature that promoting autonomy of adults with PMLD. Credibility of findings was also enhanced by providing a detailed account of the research process and by illustrating findings with excerpts from participants' interviews. Robson (2011) believes that this guards against suspicions of basing the interpretation on a selective and biased reading.

6.2. Conclusion

Analysis of participants' interviews brought to the fore some taken for granted meanings of being a LD nurse in promoting autonomy of adults with PMLD. LD nurses now work in a whole new context to that of institutionalisation. Service philosophy has changed, beliefs and values have shifted along and most significantly the environment is now different. Three main themes emerged; 'taking responsibility', 'care delivery' and 'personhood'. The study's finding describe the qualitatively different ways in which various LD nurses experienced, understood, and interpret their experience of promoting autonomy of adults with PMLD.

These findings are relevant to LD nurse and other professional or carers that look after people without or who have lost capacity due to several reasons including dementia and brain injury. The researcher acknowledges that findings from this study are neither final nor intended to be statistically representative or generalizable to the wider study population but are interpretations that emerged from researcher-participant inter-subjectivity within a particular context. Meanings of human experience are often hidden and taken for granted and the embeddedness of LD nurses in prior network of significant relations and contexts, layered with being socialised individuals means that explication of meaning of an experience requires explicit interpretation of another's actions in a reflexively appropriated background (Hans-Herbert, 2007). Hermeneutic phenomenological research framework of inquiry has been appropriate for exploring knowledge and meanings embedded in LD nurses lived experience of promoting autonomy in adults with PMLD. Hermeneutic phenomenological inquiry does not fragment the experience that is being studied and provides descriptions that are rich and full and interpretations that illuminate what it means to be a person in that life-world.

Participants within this study revealed the difficulties involved in eliciting the views of people with profound and multiple learning disabilities owing to not being able to directly communicate a choice. They valued knowing the person as a way of promoting his autonomy and this can be

achieved by using a wide range of assessment tools and utilizing different information sources. Equally important is having the right attitude towards adults with PMLD and this requires that stereotypes LD nurses have about this client group in general and about the person in particular are exposed and challenged. This can be addressed at policy level and educational/professional development to preserve and enhance 'social-personal-professional integrity' of LD nursing profession. It is therefore important that learning disability nursing discipline develop a clear and powerful value base for the provision of care and support of adults with PMLD that embraces the virtues of community living while upholding the rights and civil liberties of this client group. As a methodology to inquiry into lived experiences, hermeneutic phenomenology is a useful research methodology for describing and gaining insights into meaning, understanding and interpretation embedded and entrenched LD nurses experience of promoting adults with PMLD.

This study used one-off interview strategy in data gathering and this may have limitations on the richness of data collected. Longitudinal or sequential interviews will have potential benefits that include the ability to collect data at different time points capturing the evolving experience of participants and track changes and gaps. Sequential interviews generates richer data the increased trust that develops over time between researcher and interviewee will facilitate more in-depth and better quality data.

As with all qualitative studies, data findings from this qualitative research will be subjective and context depended in nature making data and findings not replicable. However, reader and other researchers are invited to take interest in this area of huge significance upon the quality of life of adults with PMLD.

6.4. Dissemination of results

Findings from this research are primarily for the purpose of a MSc by Research degree thesis, copies of which may be held by the university as electronic and reference only library print copy. The research report will be written by the researcher under guidance of research supervisors and

remains the intellectual property of the University Huddersfield. University of Huddersfield reserves the right of priority to purchase the research report. The University will then decide on how to disseminate the findings. However, it is important to clarify that the researcher has no commercial interests in carrying out this research.

The researcher expects to submit work originating wholly or in part from the research findings for publication in an academic or professional journal. Publications from this study will be targeted at an audience of nurses who work with PMLD but may also be useful to all stakeholders involved in the care and support of this client group. Findings may also be useful to those who care and support other individuals deemed to lack capacity for several reasons including degenerative neurological conditions, mental illness and brain injury. The research abstract or poster may also be presented at a relevant professional's conference.

Findings from this study will be presented as a MSc by Research thesis and an abstract of the study may be submitted for presentation at a relevant professional's conference. In addition, it is anticipated that the research report may, at some point, be published in a professional or academic journal. However, should this happen, participant's anonymity will be ensured.

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Appendix 1: Participant information sheet

What are the experiences and perceptions of Learning Disability Nurses in promoting autonomy of adults with profound and multiple learning disabilities (PMLD)? *A hermeneutic phenomenological study in England.*

INFORMATION SHEET

You are being invited to take part in this study, '*What are the experiences and perceptions of nurses in promoting autonomy of adults with profound and multiple learning disabilities (PMLD)? A hermeneutic phenomenological study in England*'. Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

Information about the research

The focus of this study is on subjective experience and individual perceptions with the aim being to analyse and understand how Learning Disability Nurses (LDNs) feel, view and perceive their experiences in relation to promoting autonomy of adults with profound and multiple learning disabilities (PMLD) who live in England. Promoting and establishing autonomy of adults with PMLD is a key aspect of empowerment and civil liberties. It has been interpreted and operationalized in local service policy and procedures, national policy, moral values, professional responsibilities, national legislation and international treaties in broad terms to mean; (1) choice and control; and (2) individualisation and realisation of one's own aspirations. Both 'choice and control' and individualisation are key tenets of current service provision and developments for people with learning disabilities. Valuing people now (2009) recognises that some individuals with learning disability will require support to exercise this right. However, it is not uncommon to discover that those with PMLD are least beneficiaries and often excluded from these developments.

For the purpose of this study, what constitute 'promoting autonomy' is considered to be any action or nursing intervention, in isolation or combination, that has actual or perceived outcome intended to safeguard the rights, wishes, aspirations and civil liberties of this client group while advancing and increasing individual's capacity for decision making. Promoting autonomy is a matter of concern to almost all healthcare professionals and family members alike who offer support and treatment to adults deemed mentally incapacitated to make specific decisions, but perhaps most notably those with profound and multiple learning disabilities. Similarly, having a clear understanding of the what 'promoting autonomy' means has been regarded in empirical literature and policy documents as a matter of high importance and consequence upon the nurses' perception of their professionals responsibility regarding related decisions and experiences in caring activities.

Data collection method will be unstructured and face-to-face interviews. The interviews will be audio recorded lasting approximately 60 minutes. Participant's place of work will be the primary location for conducting the interview. Where participants feel uncomfortable to share their experiences within their work area, alternative locations will be considered including University of Huddersfield research hub meeting rooms and other suitable local ad-hoc meeting room hire facilities.

By taking part in this research, the researcher hopes that findings from this study will contribute to evidence based practice by providing in-depth insights and illumination on the Learning Disability

Nurses' understanding, meaning, interpretations and perceptions of their experience in relation to promoting autonomy of adults with PMLD. It is also hoped that the study findings will stimulate debate in the area and promote further research that would enhance the quality of care delivered.

Why I have been approached?

You have been asked to participate because of your role as a Learning Disability Nurse involved in supporting and promoting autonomy of adults with profound and multiple disabilities.

Do I have to take part?

Participation in this research is voluntary. If you decide to take part you will be asked to sign a consent form. As a participant, signing the consent form is not an obligation to continue in the role, if at some point, you no longer wish to do so. It is within your right to withdraw your consent at any time without giving a reason.

Expectations about the participants.

As a participant, you would be expected to take part in a face-to-face interview and share your experience in relation to promoting autonomy of adults with profound and multiple disabilities. The interview uses open ended questions and does not follow a fixed structure. Instead, questions asked will depend on your descriptions and explanations of your experience.

What are the risks?

There is no direct risk to you taking part in this study. However, the research method involves reliving and descriptions of experiences some of which may cause emotional and psychological distress. The research has been designed to minimize the risk and ethical approval has been sought from the University of Huddersfield School Research and Ethics Panel. An up to date risk assessment will be maintained throughout the research process.

Confidentiality, anonymity and security of data

Your confidentiality and anonymity will be respected throughout the process except of cause during face-to-face interview when it is not possible to maintain your anonymity. However, you need to be aware that the researcher will be duty bound to report safeguarding matters, actual or suspected, where law has been broken to responsible agencies in discussion with the research supervisor. This overrides any confidentiality agreements made. Data collected will be anonymously transcribed and stored using a coding or numbering system. Password only access will be used for all computerised data and external hard discs and printed materials will be stored under lock and key. Sheet with linking identifying personal information will be stored securely and separately from all other data to ensure irreversible identification of participants. Measures will be taken to ensure that data collected will not be published in a form which would allow actual or potential identification of yourself. Your data will not be stored for longer than necessary, or used for any other purposes other than this study only and on completion of the study, data collected will be destroyed after 6 months in accordance with The University of Huddersfield Policy.

What will happen to the information?

Findings from this study will be presented as a MSc by Research thesis and an abstract of the study may be submitted for presentation at a relevant professionals conference. In addition, it is anticipated that the research report may, at some point, be published in a professional or academic journal. However, should this happen, your anonymity will be ensured.

What are the costs?

There are no financial costs to you associated with taking part in this study. The researcher will not be able to remunerate you for any expenses incurred by taking part in this research.

Who can I contact for further information?

If you require any further information about the research please contact Principal Researcher:

Pedzai Tsungu , *RNLD, BSc Hons, MSc by Research student*, University of Huddersfield, Queensgate, Huddersfield, HD1 3DH. u0962651@hud.ac.uk Tel: 07533879773

Appendix 2: Invitation letter (Participant)

Place of work: ……..

Date: ……..

Dear ……

I am writing to invite you to take part in a study I am conducting exploring the experiences and perceptions of Learning Disability Nurses in promoting autonomy of adults with profound and multiple learning disabilities.

The study is titled: **What are the experiences and perceptions of Learning Disability Nurses in promoting autonomy of adults with profound and multiple learning disabilities (PMLD)?** *A hermeneutic phenomenological study in England.*

The aim of the study is to develop an understanding and insights into the perspective, meaning and interpretations of Learning Disability Nurses' experiences in promoting autonomy of adults with profound and multiple learning disabilities. For a detailed brief about the study please see the attached '*Participant information sheet*'. I have also attached a '*consent form'* to be completed if you wish to participate.

Participants involved will be interviewed on their experience in relation to promoting autonomy of adults with profound and multiple learning disabilities who live in England.

The study has been approved by the University of Huddersfield's School Research Ethics Panel, and your organisation's Learning and Development Office. The study has also been considered by NHS Proportionate Ethics Reviewer Manchester Office as not raising matters of ethical concern.

The research's final report will be submitted as a Masters by Research Thesis. It is also expected that findings from the study will be published in an academic or professional journal as well as presented at a relevant professional conference in the form of an abstract or poster.

I appreciate your time and attention to my study. I look forward to hearing from you

Please do not hesitate to contact me if you would like further information.

Yours faithfully

Pedzai Tsungu
RNLD, BSc Hons , MSc by Research student.
Centre for Health and Social Care Research
School of Human and Health Sciences,
University of Huddersfield,
HD1 3DH,
Tel: 07533879773, email: u0962651@hud.ac.uk

Appendix 3: Letter seeking permission

[ADDRESS]

RE: What are the experiences and perceptions of Learning Disability Nurses in promoting autonomy of adults with profound and multiple learning disabilities (PMLD)? A hermeneutic phenomenological study in England.

Dear **[NAME OF MANAGER]**

I am writing to seek your support for a study that I would like to conduct on the experiences and perceptions of Learning Disability Nurses in promoting autonomy of adults with profound and multiple learning disabilities.

The aim of the study is to develop an understanding and insights into the perspective, meaning and interpretations of Learning Disability Nurses' experiences in promoting autonomy of adults with profound and multiple learning disabilities. For a detailed brief about the research please see the attached 'Participant information sheet'. I have also attached a consent form.

Participants involved will be interviewed on their experience in relation to promoting autonomy. Details of the interview are attached. Please see the 'Interview Schedule'.

The research's final report will be submitted as a Masters by Research Thesis. It is also expected that findings from the study will be published in an academic or professional journal as well as presented at a relevant professional conference in the form of an abstract or poster.

I am seeking your permission to advertise for recruitment of participants in your services. The design of the study is intended not to impact on your resources. The study has been approved by the University of Huddersfield's School Research Ethics Panel (SREP), Your local Research and Development Office and has been considered not to be raising matters of ethical concern by NHS Proportionate Ethics Reviewer Manchester Office.

I appreciate your time and attention to my study. I look forward to hearing from you

Please do not hesitate to contact me if you would like further information.

Yours faithfully

Pedzai Tsungu,
RNLD, BSc Hons , MSc by Research student. Centre for Health and Social Care Research
School of Human and Health Sciences, University of Huddersfield, HD1 3DH, Tel:7533879773, email: u0962651@unimail.hud.ac.uk

Appendix 4: Consent form

CONSENT FORM

Research Project: **What are the experiences and perceptions of nurses in promoting autonomy of adults with profound and multiple learning disabilities(PMLD)?** A hermeneutic phenomenological study in England

It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate, if you require any further details please contact your researcher.

I have been fully informed of the nature and aims of this research □

I consent to taking part in it □

I understand that I have the right to withdraw from the research at any time without giving any reason □

I give permission for my words to be quoted (by use of pseudonym) □

I understand that the information collected will be kept in secure conditions for a period of five years at the University of Huddersfield □

I understand that no person other than the researcher and research supervisors will have access to the information provided □

I understand that my identity will be protected by the use of pseudonym in the report and that no written information that could lead to my being identified will be included in any report. □

If you are satisfied that you understand the information and are happy to take part in this project please put a tick in the box aligned to each sentence and print and sign below.

Signature of Participant:	Signature of Researcher:
Print:	Print:
Date:	Date:

Appendix 5: Interview protocol

Title of Research Project: **What are the experiences and perceptions of nurses in promoting autonomy of adults with profound and multiple learning disabilities (PMLD)? A hermeneutic phenomenological study in England.**

Pre-interview stage

About the researcher and purpose of research:

My name is Pedzai Tsungu, I am a PGR student at the University of Huddersfield on a Masters by Research degree, School of Human Health and Sciences. Conducting this research is part of the requirements for a successful completion of the degree. I am also a practicing Learning Disability nurse working with adults with mild to severe learning disabilities and multiple needs.

This research explores the experiences of nurses involved in supporting and promoting autonomy of adults with profound and multiple learning disabilities. It seeks to analyze meaning and understanding ascribed to the experience as perceived by the nurse. It is hoped that findings from this research will contribute to evidence based practice by illuminating ways in which nurses promote autonomy of adults with PMLD and stimulate debate in the area.

I would like to thank you for your time and the interview will take approximately 60 minutes and will include questions about your experiences in relation to supporting and promoting autonomy of adults with profound and multiple learning disabilities.

Consent

The interview will be implemented on a face-to-face basis within participant's place of work. The interview will be unstructured and uses a series of open ended questions. The interview will take approximately 60mins and will be audio recorded

Participant will be informed that participation in this interview is completely voluntary and that consent can be withdrawn at any at any time (for the whole or part of the research) without giving any reason.

Participant will be given plenty of time to read through consent form and 'participant information sheet'. The researcher invites any questions about the research, only proceeding with the interview after consent has been granted.

Interview stage

The interview opens with a broad open question: Description of experience

[1] 'Can you describe' / 'can you tell me about' your experiences of being involved in supporting and promoting autonomy of adults with PMLD?

Context: *[Based on a particular experience/situation or example]*

[2] Can you tell me about the nature relationship you had with a respective client, their significant others and other professionals involved in the process of deciding and making choices?

Exploring meaning and perception of experience

[3]How do you view your experience?

[4] How did you feel about the outcome of decision or choices made? *[To explore state of mind; how things sounded, feelings, mood emotions, etc]*

[5] How well do you feel you have been able to support the client? *[perceived quality of support]*

[6] What was the impact of the decision or choices made on your practices?

[7] What impact did your experience in the process of deciding and making choices have on your role within you team?

[8] How has your experience changed your view of things?

Knowledge and understanding of autonomy of adults with PMLD

[9] What does autonomy mean to you?

[10] What is your perspective on developments around issues of supporting and promoting autonomy of people with PMLD?

[11] How has your understanding of the concept of autonomy change over the time/years since you qualified as a learning disability nurse?

[12] Can you tell me about your early experience of supporting and promoting autonomy of people with PMLD?

[13] Tell me the ways in which you have dealt with any difficulties you have experienced in relation to autonomy?

Interview closing

Thank the participant for sharing their experience. Provide contact information and relay to the participant that they can contact the researcher if they think of something later that might be relevant to the research. Also hint that there may be a subsequent contact if there is a need for clarification to information provided or to ask additional questions.

Appendix 6: Risk assessment

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: Data collection: Interviewing, observing and conversations with participants			Name: Pedzai Tsungu	
LOCATION: Participant's place of work			Date: 20/05/2013	Review Date: 20/04/2014
Hazard(s) Identified	**Details of Risk(s)**	**People at Risk**	**Risk management measures**	**Other comments**
Sensitive issues or distressful events may be brought up during interviews	Psychological and emotional well being	Participants	• The research will designed to ensure that physical and psychological wellbeing of participants will not be adversely affected. • Researcher to exercise own discretion in discussing sensitive issues with participants. • Where potential for emotional distress is forthcoming, the participant is able to withdraw from the study if required. • The researcher will lay out the potential for distress to prospective participants during the preliminary meeting prior to conducting the interview or during the recruitment stage. Participants are made aware that they may withdraw their consent to remain in the role without giving a reason. • Disclosure of safeguarding issues by participants will be discussed with the research supervisor and discretion exercised in reporting to responsible agencies.	Participants will particularly be reminded of the possible sensitivity of the research topic and issues that may be brought up during the interview The researcher has access to training and preparation skills for interviews, as well as supervisions. The researcher will also act in accordance with the University of Huddersfield **'Ethical Guidelines for Good Practice in Teaching & Research'** Where required, referral will be made to the participant employer Welfare services or the University of Huddersfield's counseling services.

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: Data collection: Unstructured interviewing of research participants			**Name: Pedzai Tsungu**	
LOCATION: Participant's place of work			**Date: 20/05/2013**	**Review Date: 20/04/2014**
Hazard(s) Identified	**Details of Risk(s)**	**People at Risk**	**Risk management measures**	**Other comments**
Display screen equipment	Poor posture sat working for prolonged periods resulting in musculosketal problems, visual/physical fatigue	Researcher	All workstations subject to DSE assessment process	
Travelling (using own transport)	Bad weather, poorly maintained vehicle and tiredness may result in an accident	Researcher	Planning journey well in advance. Being aware of the weather outlook. Allowing plenty of rest during a long journey. Ensuring that the vehicle has a valid MOT, road tax and a suitable insurance cover.	The researcher will negotiate with participants suitable setting/place for interview including time of day.
Interviewing in the work places of interviewees where service users my present with challenging behaviours.	Personal safety	Researcher	Log times and date of interviews and observations with colleagues / administrator Phone call into the Human and Health Sciences administration /colleagues on leaving visit. If out of office hours or at the weekend I will inform a responsible friend/family member where I am going and arrange to text them on leaving participant's premises.	Specific interview arrangements and location will be identified with administrator/colleagues in advance of meeting. The researcher has up to date training in certain areas of managing aggression and violence. These will be discussed with the participants
Loss/ theft of data	Security of data	participants	Electronic data to be stored only on password secured computer equipment and storage devises. Dictaphones with audio recordings to be transported in a lockable case. Data stored will be destroyed once it is no longer required for the purpose of the research or has been stored for a period longer than 5 years. Whichever is earlier.	Laptops, and other electronic data storage devises to be transport in the boot of a car.

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: Data collection: Unstructured interviewing of research participants			**Name:** Pedzai Tsungu	
LOCATION: Participant's place of work			**Date:** 20/05/2013	**Review Date:** 20/04/2014
Hazard(s) Identified	**Details of Risk(s)**	**People at Risk**	**Risk management measures**	**Other comments**
Researcher's safety	Personal safety	Researcher	The researcher will comply and adhere to the University of Huddersfield 'Lone Worker Policy during field work. The research will be conducted lawfully, with honesty and integrity, and in accordance with good practice as set out in the 'Good practice in research' (GMC, 2010) The research is based on a carefully developed protocol backed up by evidence and has been approved by the University of Huddersfield School Research Ethics Panel (SREP) Ensuring both the researcher and participant are informed and prepared to address distressful issues that may arise as data emerges. Where possible and within the limits of the study, to establish a trusting and enduring relationship with participants. Using reputable locations, with a good staff presence or security presence who can come to researcher's assistance when required. Knowing how to call security and having access to a phone. If the danger is direct to dial 999 Not taking any valuables unless there is a need to. This includes keeping possessions (bags and any	The risk is particularly high when researching sensitive topic and working alone (one-to-one interviewing) The potential to cause emotional of psychological harm to participants due to the nature of in-depth interview and sensitivity of the research topic has been highlighted in the participant information sheet. Participants will be asked to take this into consideration in deciding whether or not to take part in the study. Potential participants will be given the opportunity to decline to be interviewed. Also unstructured interview means the researcher is not able to predict the direction of the interview and matters that may be arise in the course of

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

			valuable equipment) in a safe place and knowing where it is at all times. Should a participant became distressed, consideration will be made to either take a breather for a few minutes or terminate the interview and where appropriate referral made to services for support and counselling. During the interview the researcher will be very attentive to potential indicators of being emotionally distressed. Avoiding interrogating participants and treat participants with respect and sincere interest in the shared experience. The researcher will engage in self reflection and debriefing with supervisor to explore personal responses and consider potential situations that may compromise researcher's safety Knowing emergency procedures in case of a fire and where fire exists are. Keeping a log of locations, route and expected time of return. Have a check in system with the research office or a friend. Always carrying an identification badge on the person and wearing appropriate clothing Attending relevant training such as assertiveness and interviewing skills	the interview The research study has been reviewed and approved by the University of Huddersfield School Ethics Panel (SREP) The researcher to adopt considerate approaches at all times and offer reassurance if required. This will encourage participants to discuss sensitive issues in open and sensitive manner (Denscombe, 2010)

Appendix 7: Dieckelmann, Allen and Tanner (1989) data analysis approach

Dieckelmann, Allen and Tanner (1989) data analysis approach analysis involves seven steps:

(a) reading the interviews to obtain an overall understanding;

(b) writing interpretive summaries and coding for emerging themes;

(c) analysing selected transcripts as a group to identify themes;

(d) returning to the text or to the participants to clarify disagreements in interpretation and writing a composite analysis for each text;

(e) comparing and contrasting texts to identify and describe shared practices and common meanings;

(f) identifying patterns that link the themes; and

(g) eliciting responses and suggestions on a final draft from the interpretive team and from others who are familiar with the content or the methods

Appendix 8: Interview Transcript

Interview 9 Full transcript

R: Researcher and P.9: Participant

R

[this follows pre interview conversation explaining what the interview is about and how it will be conducted] …… I am looking for your experiences in supporting someone with their autonomy on the severe and profound end of the spectrum

The type of this interview is called unstructured so its entirely up to you what you want to tell me about your experiences [in relation to topic of interest and participant was made aware to describe in as much detail as allowable]

P9

It is about what experiences I have as an LD nurse, how I see autonomy of the people we support. I have worked as an LD nurse since [year deleted] in this kind of area (day service) working with people with complex needs. That is [No. deleted] years. Obviously I have been working in this sort of area which is adult day service, a Monday to Friday service and people access this service from home Monday to Friday. That's predominantly the service I have been working in all these years.

Here [name of place of work deleted] we have [name of service deleted], we have adult education and an inpatient service at [name of hospital deleted]. We work across all those areas but we will soon be assuming a new role as community nurses as well as physically working in a day service. We will also be working in a respite unit [name of unit deleted] at [name of hospital deleted]. Mostly people who go to the respite service access this day service so we know them well. So at the moment we have got a varied role. Here at day service we work directly with clients, giving nursing interventions, assisting with practical stuff, advising staff and paid or volunteer carers. We also do that in the community with carers and family and we do that in a multidisciplinary system. Generally that's what we do.

Because we normally work with people here Monday to Friday, people we have known for a very long time we obviously know the individual quite well and because of the complex learning disabilities, physical and health needs and if people do not know them that well and there is some inconsistences in staff at least we sort of know that person quiet well and can observe any changes from a physical point of view. We can pick up on that quiet easily. That is important because the person may not be able to verbalize or communicate. There may be subtle signs, the person may be sleeping more or not eating well or the behaviour has changed, so we can sort of pick up on those sort of cues from having known the person really well in

comparison to those who don't work with the person that often, say a community nurse who may go on a visit. So we are quiet fortunate we have got that knowledge about that person then obviously we can pick up on things.

Communication is obviously a massive barrier for people we work with but usually for people we work with you can normally guess sometimes what the person is thinking. We can sometimes anticipate a need, but usually it's a physical response, maybe if they are uncomfortable in the chair, they need a position change or if it's on the personal care point of view. We can pick up on those sort of things. People we work with are mostly non-verbal and in terms of giving power and responsibility and choice we would hope that as a carer we can think of these things from the carers perspective and from that person's point of view, to consider options I suppose for that person but its difficult to get sort of more in-depth communication.

From an understanding point of view on more complex issue other than day to day things. So in terms of empowering people, I hope we would empower people but in terms of capacity I suppose that is when it is quite difficult for us (LD nurses). Certainly when working with other families and carers and other professionals its almost like if a person does not have capacity, they do not understand. At least we are not making a single decision in isolation for that person you are involved in.

So autonomy I think its quiet hard, its an alien concept. You would hope that everybody would strive to give as much autonomy to that person as much as they could. In terms of their understanding, receiving information and retaining information and making decision based on those facts but still I find it very difficult. Say for example there is one person that we work with, the only thing that she communicates with and I suppose its communication really. All she does is she puts her head forward. A few years ago she did used to grimace and turn her head away when she was eating and that was another physical response she could do. Another physical response when her feet were hurting, she would draw her legs up to the body but they are all physical responses. So its very difficult to determine that person's level of understanding although we would always speak with somebody as if they are understanding. We always speak to somebody what we are doing and why we are doing it but for that person to have any control of that it is very difficult.

R

Its difficulty to elicit the person's understanding

P9

Thinking of another example where the person has control over [pause] A number of people we are looking after live with family and often the family can be the decision maker for that person. Often, whether rightly or wrongly, whether we would agree or disagree. You can sometimes have strong family members with

strong opinions about things and that can be obstructing to things like treatment. They may disagree that wheelchair is not right for the person even if the person has been to the wheelchair centre and the physiotherapist, and occupational therapist have approved it as the best for that person's postural support. Sometimes you might get a family member who might say I don't agree so the person is in the middle.

Obviously they live with family, as long as they are able to live with family and as long as the family is able to provide care for their son or daughter and as I say they are still dependent, they do not have any sort of independence in a way from that. So I would say the control is with the carers really in terms of autonomy.

Thinking of other situations you would not take autonomy for the person. You still look at their quality of life and choice and opportunity certainly for the person, you would not restrict those in any way and even you would look to improve the quality of life for somebody and would still look at taking risks for that person if you thought the benefits are there for that person. So you are looking at factoring in Risks. Knowing obviously we would reduce such risks so they could not go out or could not access this. So we still have to say calculate risks in terms of activity the person may want to be involved in or like. I suppose its about health, and same is for everybody like you and I our autonomy is taken away in terms of specialists, doctors and consultants. We rely on people to give us good advice. We still should have choice.

R

We do not usually know it is happening, I was explaining to my wife about this [topic being explore] that when you go to your GP the organ donation for example, you have to opt out and not everybody is aware of this and they have taken your autonomy.

P9

That's it, often in our life we feel that we are autonomous ourselves. Even when you are admitted into a hospital you are seen as a patient and a lot of that is sometimes taken away but we would still be able to question why, whether there were options, what is happening, whether there were alternatives, what benefit will this be in comparison to somebody else. So really we are looking at a best decision for that person based on that person's cognition, circumstances and the health. What we try to think about is knowing the person really well, like we would know from the person. For example if somebody is quiet awkward in public places, if its really loud and their behaviour reflects that they do not really like it, maybe they self harm or stop smiling or they become suddenly subdued. We can take that if it happens over a long time and we can say they do not like loud music, they don't like busy places but not to say that you would always think that for the person. It could just be because of the mood that they are in, it is about giving that person the opportunity to experience that another time and things might change. Sometimes we make assumptions that when people's behaviour change that they show a dislike.

So in a way obviously the more people can communicate or give facial expressions or make noise or their body language, the more the person can show us dislike of something or a particular like of something, that we can adjust what we do and how we do it with them. Although there is physical and nursing intervention that has got to happen for that person. For example nutrition if you have somebody who is nil-by-mouth and has a gastrostomy, the decision for them to have a gastrostomy has been a best interest decision with a doctor in hospital and other people involved with that person and they obviously at that point come to agree or disagree to that but you make that decision based on the person getting good nutrition, skin will be good, the medication will work better and all those sort of things. For example we had a gentlemen who had a PEG, a gastrostomy tube. This gentlemen had a PEG and was at a point of having it change and have a button, but at the point of him having a new button, he was pulling it out and this person would not eat or drink. In a way would you classify that as him making a decision that he did not want it. However, if that was not replaced with another PEG nutritionally he would not have survived. So that was a difficult decision to say we have to replace it otherwise he would have not been able to get his nutrition. They used best-interest meetings involving family and others involved in the care of this gentlemen.

Things like people's finances are not managed by themselves either they are managed by the family as well. For us (LD nurses) its about making decision about what drink they have , tea or coffee, whether they want a cold or hot drink. Autonomy is at a very basic level, certainly, its not that it should be. We all agree that people should make choices if they understand the implication of the choice. Like I said, generally, our work here is about basic needs really not anything more complicated than that.

In terms of the person's care as a trust we have standard care plan meetings which happens certainly on a yearly basis and more regularly so when the needs of the person changes in any way and that gives the opportunity for everybody including the person if they were able to talk about what care they are getting and if there is any changes that is needed. That is looked at from a group approach constituted by those involved in the care of the person. So that is sort of ongoing in terms of the care that the person gets and how its delivered and who delivers it [Pause and digression].

I am trying to think of every little thing that makes person's autonomy. It is usually day to day things for example knowing that you are comfortable in a chair. But this is about choice more than autonomy, they sort of somehow indicate a need and its based on need than being totally in control

R

What is your perception of expressing choice on what is happening now and long term choices?

P9

Long-term choices. For example where people live and who they live with often changes and such choices have to be made at some point, certainly, with ageing population and things like that. But a lot of things, and its my view, its about resources, services and financial. People being in charge of budgets etc. In terms of long-term choices for us (LD nurses) its about where people live, holiday they could access and day care services. That is not always governed by the person and the family's needs. It is about budgets and how much it cost to travel from there to the other side of the city when that service could be suited for that person. There is financial restraints. Things like direct payment are a better option for certain people. Direct payments has been happening for the last couple of years so that people can take charge of their care for the particular person whether from a particular service or by employing somebody.

There where 150 people within this service originally and now there is only 50 left here. The rest have been relocated and I don't know how much choice they have had on that. It is about developing services and moving forward. I suppose often people with less complex LD would voice their preferences I terms of where there would like to go if there was a choice of services available to them. There has been planning meetings to involve people we support [in the process of deciding where to be relocated as the service will be closing late this year or early next year]. We are having planning meetings because we are moving to [Name of Place deleted ….. approximately 5 miles away] to a new building. So there is decisions to be made whether the people we support here will be moving with us. We have had to fight for some people to either come back with us or access other services. We have had to advocate for them even though it may be a long way for them to travel, their needs won't be best met in their local services. Only if they could voice their own. I think we know them well enough to know what they would prefer. Families and Adult Social Care are involved in that.

Interview ended with a general talk on the topic of interest which is not relevant to textual basis for analysis but important to lessen participant's anxieties while allowing the researcher to answer any further questions about the study that may have risen in the course of the interview. Participant is thanked for the contribution.

Appendix 9: SREP authorisation

Your Amended SREP Application - Pedzai Tsungu (MRes Student) -

APPROVED SUBJECT TO RECEIPT OF LETTERS OF PERMISSION - What

are the experiences and perceptions of nurses in promoting autonomy of adults with PMLD? (Ref: SREP/ 2013/47)

Kirsty Thomson

nt: 07 August 2013 11:49

To: Pedzai Tsungu U0962651

Cc: Rob Burton; Niall Dew; Karen Ousey; Nigel King; Jodie Matthews

Dear Pedzai,

Dr Jodie Matthews, Acting SREP Chair, has asked me to contact you with regard to your amended SREP application as titled above.

Dr Matthews is satisfied that you have addressed the issues raised, however, for advice, the additional paragraph you have added in the Information Sheet should be checked for grammatical errors.

We await receipt of your letters of permission prior to being able to grant full ethical approval.

Regards,

Kirsty

(on behalf of Dr Jodie Matthews, Acting SREP Chair)

Kirsty Thomson

Research Administrator

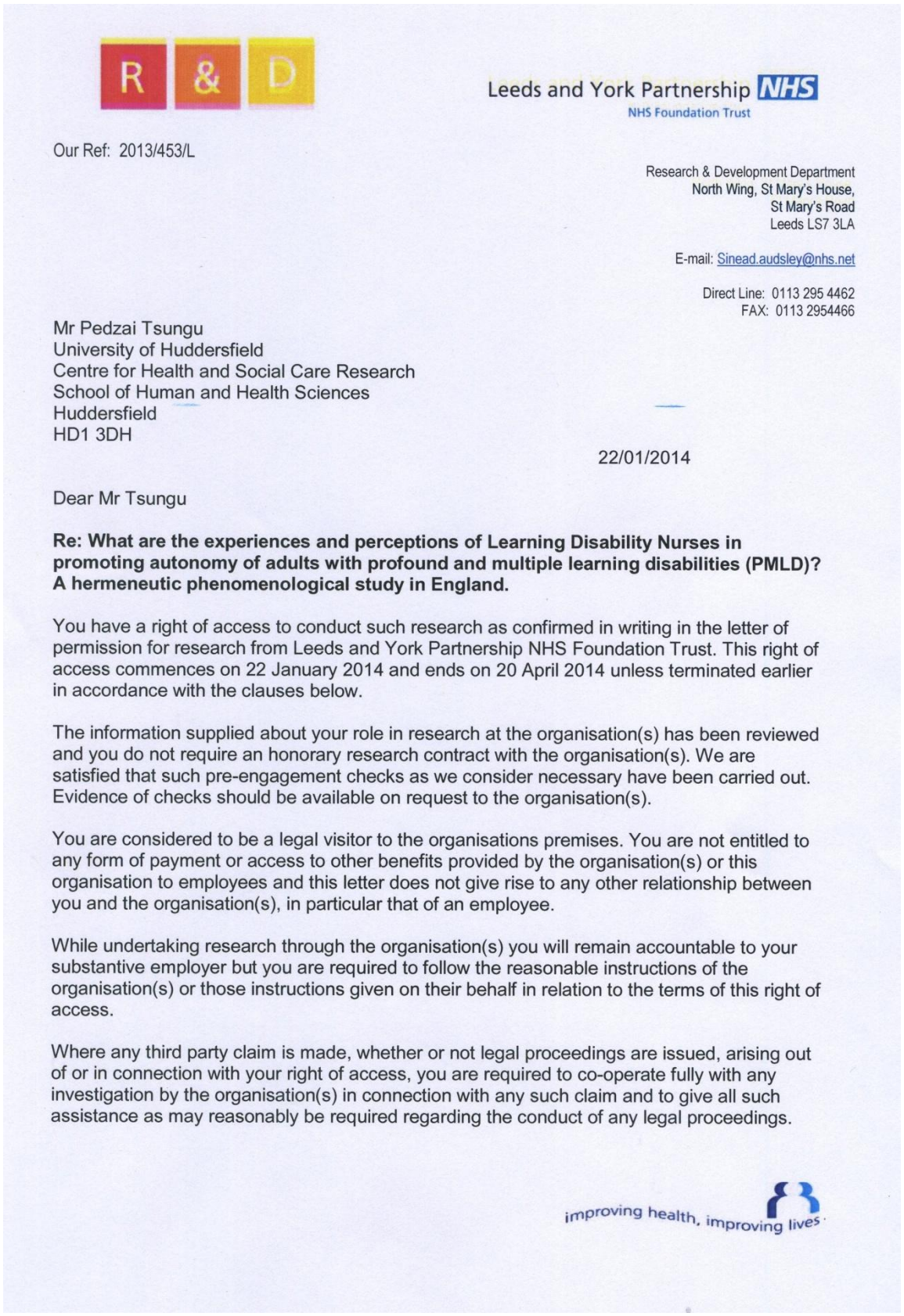
\..: 01484 471156

IS1: K.Thomson@hud.ac.uk

M: www.hud.ac.uk

School of Human and Health Sciences Research Office (HHRG/01) University of Huddersfield I Queensgate I Huddersfield I HDl 3DH

Appendix 10: NHS R&D Letters of access



R & D

Leeds and York Partnership NHS
NHS Foundation Trust

Our Ref: 2013/453/L

Research & Development Department
North Wing, St Mary's House,
St Mary's Road
Leeds LS7 3LA

E-mail: Sinead.audsley@nhs.net

Direct Line: 0113 295 4462
FAX: 0113 2954466

Mr Pedzai Tsungu
University of Huddersfield
Centre for Health and Social Care Research
School of Human and Health Sciences
Huddersfield
HD1 3DH

22/01/2014

Dear Mr Tsungu

Re: What are the experiences and perceptions of Learning Disability Nurses in promoting autonomy of adults with profound and multiple learning disabilities (PMLD)? A hermeneutic phenomenological study in England.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from Leeds and York Partnership NHS Foundation Trust. This right of access commences on 22 January 2014 and ends on 20 April 2014 unless terminated earlier in accordance with the clauses below.

The information supplied about your role in research at the organisation(s) has been reviewed and you do not require an honorary research contract with the organisation(s). We are satisfied that such pre-engagement checks as we consider necessary have been carried out. Evidence of checks should be available on request to the organisation(s).

You are considered to be a legal visitor to the organisations premises. You are not entitled to any form of payment or access to other benefits provided by the organisation(s) or this organisation to employees and this letter does not give rise to any other relationship between you and the organisation(s), in particular that of an employee.

While undertaking research through the organisation(s) you will remain accountable to your substantive employer but you are required to follow the reasonable instructions of the organisation(s) or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the organisation(s) in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

improving health, improving lives

You must act in accordance with the organisations policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with the organisation(s) in discharging its/their duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on the organisations premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each organisation prior to commencing your research role at that organisation.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the organisations premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) do not accept responsibility for damage to or loss of personal property.

This organisation may revoke this letter and any organisation(s) may terminate your right to **attend at any time either by giving seven days' written notice to you or immediately without** any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

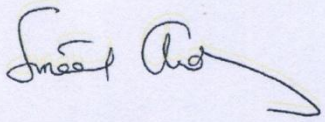
Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

No organisation will indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal

procedures. You must also inform your nominated manager and the R&D office in this organisation.

Yours sincerely



Sinead Audsley
Research Governance Manager

cc: Julie Howard
Georgina Hill, HR Department, LYPFT

Appendix 11: St Anne's Community Services authorisation

FW: university research

Pedzai Tsungu [Pedzai.Tsungu@st-annes.org.uk]
Sent:19 January 2014 23:52
To: Pedzai Tsungu U0962651
Cc: tpedzai@yahoo.co.uk

From: Tony Beech
Sent: 14 January 2014 11:08
To: Pedzai Tsungu
Subject: university research

Hi Pedzai,

I can confirm that I am happy for you to conduct your research within St Anne's services in Kirklees as part of your masters degree by research. This would be as per the terms we have previously discussed.

Kind Regards
Tony

Tony Beech
Area Manager
St Anne's Community Services
Edgerton Villa
22 Edgerton Road
Edgerton
Huddersfield
HD3 3AD
Telephone: 01484-550320
Fax: 01484-428967
Email: tonyb@st-annes.org.uk
Website: www.st-annes.org.uk

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