

DOCTOR OF PHILOSOPHY

Exploring the Nature of Oppression as Experienced by People with Learning Disabilities

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Award date:
2015

Awarding institution:
Coventry University

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Original citation:

Jeyacheya, D. Z. (2015) Exploring the Nature of Oppression as Experienced by People with Learning Disabilities. Unpublished PhD Thesis. Coventry: Coventry University

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Exploring the Nature of Oppression as Experienced by People with Learning Disabilities

By
Denford Zvinei Jeyacheya

July 2015



This work contained within this document has been submitted by the student in partial fulfilment of the requirement of their Course and Award

DECLARATION:

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in any part submitted it at any university for a degree.

.....

Signature

.....

Date

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Abstract

Aim: The principal aim of this qualitative research study is to gain a clearer understanding of oppression as experienced by People with Learning Disabilities (PWLD). In particular, this study investigated: 1) the nature of oppression - the typical kinds of oppression PWLD face during the course of their everyday lives; 2) the causes of their oppressive experiences; 3) the impact these oppressive experiences can have on their quality of life; and 4) their reaction - the strategies PWLD employ to prevent further oppression.

Rationale: Despite policies of deinstitutionalisation since the 1980s, many PWLD have not found social integration easy and continue to endure oppressive experiences in community-based settings. The nature/extent of this social problem has often been overlooked by researchers and practitioners.

Methods: This research was conducted using interpretive phenomenology as a methodology; an approach which influenced the study's design, method of data collection and strategy for analysing the rich qualitative findings. Semi-structured interviews were carried out across two sample populations; a group of PWLD (N=11) and a group of community-based practitioners/carers (N=11). The participants were selected through purposive sampling and the qualitative data was analysed using a specific Interpretive Phenomenological Analysis (IPA) process.

Findings: PWLD remain a deeply oppressed social group. Respondents reported experiencing multiple forms of oppression, which seem to interact in complex ways and be present throughout the course of their lives. The two key super-ordinate themes (most dominant forms of oppression experienced by PWLD) emerging from the process of IPA appear to be: 1) The life-long effects of marginalisation (social exclusion, powerlessness and existing as a socio-economic underclass) and 2) Multiple forms of victimisation (coping with exploitation, intimidation and abuse, both overt and subtle, from the public, family members and at times practitioners). Respondents believe that the underlying cause of their oppressive experiences is society's negative perception. Negative attitudes and beliefs arise from oppressive social forces such as: the use of diagnostic labels, segregated special needs education and limited opportunities for employment. These are experiences which respondents assert often do little more than spoil their social identity as human beings.

Conclusion: The findings confirm that PWLD living in the community continue to encounter negative social experiences which are pervasive. This research attempts to draw together and make sense of these experiences in terms of the concept of oppression. Through gaining a clearer understanding of the marginalised and victimised status of PWLD policy makers will be

more informed about how to respond to their social and economic needs, and in turn help alleviate their experiences of oppression.

Key Words:

Learning Disabilities, Intellectual Disabilities, Mental Retardation, Definition, Concept, Perspectives, Prevalence, Classification, Oppression, Suppression, Maltreatment, Domination, Injustice, Marginalisation, Social exclusion, Exclusion, Social, Economic, Employment, Underclass, Victimisation, Hate Crime, Exploitation, Bullying, Harassment, Abuse

ACKNOWLEDGMENTS

I would like to express my deep gratitude to my director of studies Dr Anthony Colombo for his guidance, suggestions, knowledge, experience and encouragement throughout the study period and without whom completion of this thesis would not have been accomplished.

I would also like to extend my thanks to all the participants in this study, who shared with me some of their painful and sensitive life experiences without which this research project would not have been possible. It is my hope that this thesis will not only help make their voices heard but also contribute to an increased awareness of the social difficulties facing many People with Learning Disabilities in the United Kingdom.

Furthermore, I would like to express my appreciation to many other people who have contributed to my knowledge and enriched my understanding in various aspects of the study. They include Tim Turner, Dr Martin Bollard, Dr Gurnam Singh, Dr Stephen Cowden and fellow PhD student Shirley Durell for her support throughout the project.

Finally, I wish to thank my family for their understanding, support and encouragement throughout the duration of my study.

INTRODUCTION

The principal aim of this qualitative research study is to gain a clearer understanding of oppression as experienced by People with Learning Disabilities (PWLD). In particular, this study investigated: 1) the nature of oppression - the typical kinds of oppression PWLD face during the course of their everyday lives; 2) the causes of their oppressive experiences; 3) the impact these oppressive experiences can have on their quality of life; and 4) their reaction - the strategies PWLD employ to prevent further oppression.

Throughout the literature various terms such as 'Learning Disabilities', 'Intellectual Disabilities' and 'Learning Difficulties' are used to generically describe people who have a combination of impaired intelligence quotient (IQ) of between zero and seventy and impaired social functioning acquired in childhood with lasting effect on development (Department of Health 2001:14). For the purpose of this study the term Learning Disabilities will be employed throughout.

While the term 'Oppression' is used frequently within the social care literature, its meaning is strongly contested (Cudd 2006). However, most scholars would probably agree that the term describes the various and deep rooted forms of harm or disadvantages a person or group of people suffer following systematic and unjust treatment during the course of their interactions with other individuals or groups in society (Harvey 2010; Young 1990).

The rationale for conducting this study rests on at least six principal issues:

Enhancing Positive Community Care:

Policies and practices have changed considerably and are associated with processes of de-institutionalisation. This is important to highlight considering that PWLD have a long history of being victims of oppression (Atherton 2005) and dating back until the 19th Century many PWLD were made invisible by policies of segregation and institutionalisation. The hostile attitudes and beliefs towards PWLD at that time saw thousands locked away in large institutions which were often located in isolated and distant areas away from the general population (Towell 2012). But changes during the 1970s and 1980s marked a shift in attitudes and beliefs towards this social group. The destructive effects of institutions on their lives were highlighted (Morris 1969; Goffman 1963) and in the 1990s onwards the emphasis was on changing the social status of PWLD based on a policy of community-based care. This resulted in a wave of

deinstitutionalisation and the movement of PWLD from public institutions to community-based settings (Atherton 2005). Hence, this study is part of the endeavour to ensure continuity and the process of consolidation of this positive shift.

Understanding Life Experiences through the Concept of Oppression:

Although there is considerable change in attitudes and some improvements in the lives of PWLD, the problems related to their institutionalisation have not gone away. PWLD have continued to maintain the oppressed status in terms of marginalisation and victimisation and according to Walmsley (2005), the oppressive practices in institutions have been transferred to community - based settings. Walmsley suggests that community-based care has continued to create socio-economic barriers similar to those which existed in large institutions. PWLD have remained disempowered, disrespected and not able to participate in society as full citizens. Recent reports by the Commission of Health (2006) about the abuse of PWLD in Cornwall and the incident of a single mother with learning disabilities who killed herself and her disabled daughter in 2007 after many years of abuse by youths, are some harsh reminders of the cruel toll of oppression PWLD experience in their lives. Dowson (1997) describes this situation as long-stay hospital patients or asylums without the visible high walls and for Chappell (2010) it is like PWLD have travelled a long way and yet no distance at all. With such strong voices doubting the success of the change in social status of PWLD and disenchanted with the pace of social change, Hamlin and Oakes (2008) pointed out that the life experiences of PWLD require even deeper examination. According to Abberley (1987), one such important way of achieving this is by examining these life experiences through the concept of oppression, which the author believes allows the researcher to capture the fundamental inequalities between PWLD and the general population.

Ensuring that the Voice of People with Learning Disabilities is Heard:

Thirdly, it is not only essential to recognise the significance of the presence of PWLD, but also to ensure that their voices are heard. Various authors believe community presence has not adequately translated into strengthening their voices as issues of their oppression, in many cases, are not presented from their perspectives (Holland 2008; Sorensen 2002). For this reason, Evans (1981) referred to PWLD as the silent minority and Williams (1995) and Sorensen (2002) identified them as the invisible victims to highlight this lack of direct say in matters that impact on their daily lives. Therefore, this study which is undertaken largely from the perspective of

PWLD, provides a voice to those who have rarely been heard through the traditional academic discourse (Nind 2008).

Enhancing Positive Attitudes and Awareness of Scholars and Practitioners:

We cannot ignore the fact that the attitudes of academics have been caught up in the negative stigmatising of PWLD. This is evidenced by the fact that they are at times presented as the oppressors instead of the oppressed. According to Rapley (2005), it is largely from this negative presentation that policies of segregation and institutionalisation were derived. Most notably is the work of Galton (1869) who in his book 'Hereditary Genius' advocated for the removal from society of people such as PWLD and discouraged reproduction among themselves as a measure to improve the human race. Tredgold (1909) expressed similar views and further advocated for the protection of society from the criminal tendencies of PWLD linked to notions of dangerousness, violence and unpredictability. With these views supported by politicians and governments, PWLD were widely understood as causing harm to society (Atherton 2005) and the victim side of their oppression has remained largely invisible and unaddressed (Sorensen 2002). This empirical project adds to the limited literature available, in particular the work of Northway (2007, 1997), Hall (2005), Walmsley (2005) and Abberley (1987) which addressed the social difficulties PWLD face in terms of oppression.

Contributing to improving the Quality and Volume of Research:

There is lack of good quality research to help us understand the experiences of this social group. Williams (1993) underlined this problem as far back as 1993 when the author highlighted that little progress had been made in investigating the scale and impact of victimisation of PWLD. Similarly, Sorensen (2002) suggested that the advances achieved in investigating other vulnerable people such as children and the elderly have not been replicated in the study of oppressive experiences affecting PWLD. More recently, a literature review by Horner-Johnson and Drum (2006) also confirms the existence of a small volume of literature that targets the negative social life experiences of PWLD. These authors observed that the literature was mostly ten or more years old and statements about PWLD had continued to be based on these older studies. Overall, the volume of research studying the needs of this group is probably still disproportionate to the difficulties they continue to face.

Promoting a Holistic Approach to Understanding Experiences and Life Needs:

Finally, what is needed is a fundamental change to a more holistic policy approach that places at its heart the nature, impact and significance these oppressive experiences may have across the life course of PWLD. It would seem that these have been under-estimated by practitioners and scholars (Duffy 2007). Many have remained stuck in the traditional understanding of PWLD that is predominantly shaped by the medical and intellectual/psychological approaches that emphasise biological abnormalities and limitations in physical and cognitive functioning (Shallock et al 2007). This preoccupation with abnormalities and inabilities has meant that the needs of PWLD have continued to be defined in terms of these limitations and conditions (Shakespeare and Watson 2002). This, according to Barnes (1996), does not only fail to make a distinction between experience of impairment from experience of oppression but also fails to provide a balanced emphasis between bio-psychosocial factors that impact on the life needs of PWLD. According to Wade (2009) health practitioners and researchers should consider developing a social approach that helps to achieve this balanced focus necessary to comprehend the complexities involved in understanding the multiple factors that determine the well-being and quality of life of PWLD. Therefore, this study argues that in order to ensure that social care need is treated as a critical element of any holistic or integrated care approach provided to PWLD, it is necessary to: a) Understand the nature of social care needs of PWLD; b) Integrate these needs into a more holistic policy approach of support; and c) Train practitioners to become more aware of the complex range of health/social factors that impact on PWLD's daily lives.

This research project is organised into five main parts. **PART ONE** critically reviews previous studies which have investigated the oppressive experiences affecting PWLD. This involves a critical review of the definitions of LD, definition of oppression, experiences of marginalisation and experiences of victimisation; **PART TWO** provides a detailed account of key methodological aspects of the study. This consists of chapters on the research design, sampling design, data collection methods, a detailed analysis of the qualitative data using Interpretive Phenomenological Approach (IPA), ethical considerations and a chapter on reflective practice; **PART THREE** provides a detailed presentation of the study results organised in terms of the nature and causes of, as well as the impact and reaction to marginalisation and victimisation of PWLD. **PART FOUR** presents a broader discussion of the findings suggesting policy, implications and future research directions.

PART ONE

CRITICAL REVIEW OF THE LITERATURE

The aim in PART ONE is to provide a background context to the current study. In particular we need to gain a sense of the intricacies associated with complex terms, such as, learning disabilities and oppression, and their inter-relationship. In order to achieve this aim, PART ONE is organised around four chapters. Chapter 1 reviews various definitions of learning disabilities and discusses some of the problems associated with these definitions; Chapter 2 provides a review of the different definitions of oppression and attempts to critically discuss the complexities associated with being oppressed; Chapter 3 critically reviews literature on marginalisation, an important form of oppression and Chapter 4 explores victimisation as another major form of oppression

CHAPTER 1: DEFINITION OF LEARNING DISABILITIES

INTRODUCTION

As the main respondents of this study are PWLD, it is important to clarify at the outset what constitute 'Learning Disabilities' and to highlight the nature of their difficulties. The chapter will be organised around 3 sections: Section 1 discusses the nature and prevalence of learning disabilities. A general definition of learning disabilities will be provided. Also, the impact of having learning disabilities on the everyday functioning of individuals will be highlighted. This will be followed by a discussion on the prevalence of PWLD in order to develop some insight into how widespread the condition is in the United Kingdom. Section 2 considers some important perspectives and official classifications of learning disabilities upon which some different meanings of PWLD are based. Section 3 examines the consequences of being given a label 'learning disability' including its association with oppressive experiences.

To retrieve literature for this chapter, the following databases were searched: PsycINFO, EBSCO and CINHALL. Google scholar search engine and internet websites related to learning disabilities were also accessed. Such websites included BILD, MENCAP, National Autistic Society. These were supplemented with information retrieved from books and journals. For all searches the following key words were used: Learning disabilities, Intellectual disabilities, Mental retardation, Prevalence, Definition, Concept, Perspectives and Classification.

NATURE AND PREVALENCE

General Definition:

PWLD are formally defined as people who have significant limitations in intellectual, cognitive and developmental abilities. These exist concurrently with limitations in adaptive skills (communication, social skills, self-care and use of community facilities). This combination of limitations originates during the developmental period of the individual and commences before the age of 18 years (WHO 1992; DH 2001; Harris 2005; AAMR 1992). The disabilities can be associated with delays in early developmental milestones and the related delays in intellectual

and functional development. These significantly impact on the person's capacity for self-determination and independent living (Mental Health Special Interest Research Group 2001:05). As stated by Baroff and Olley (1999:16), the general impairment in personal competency will always affect general functioning and this can be observed in the limitations in quality of thinking, difficulties with managing daily life activities and issues with individual and/or social behaviours.

Impact on Everyday Functioning:

Performing and managing daily activities of living can pose numerous challenges for many PWLD. Intellectual or cognitive impairments related to their learning disabilities can impose functional disabilities that may involve deficits in: information processing, memory, problem solving, comprehension of complex information, verbal communication, attention and in organisational skills, which can lead to social functioning difficulties (Vogel and Forness 1992). For instance, with regards to the issue of communication deficits, Nippold (2012) asserts that there is a close association between communication disorders and lack of or limited success in academic, social and vocational areas. The speech and language deficits can hinder social communication and social integration that in turn can have a serious negative impact on self-esteem and the general behaviour of the person affected (NACRO 2011). But Gerber (2012) points out that the biggest challenge for PWLD is attempting to adapt to important areas of social functioning including employment, family and education, which may be problematic without the necessary support.

Other life challenges are related to their physical health and disabilities. The presence of learning disabilities has been associated with prevalence of other physical health conditions including epilepsy (Lhatoo and Sander 2001), sensory impairments (Kerr 2004; Chappell 1998; Hatton and Emerson 1995) and musculoskeletal abnormalities (Sander et al 2007; Harris 2005). These increase risk of harm to PWLD, restrict opportunities for physical activity and independent living and influence the level of support they will require to go about their daily lives (DHSSPS Northern Ireland 2011). Furthermore, a significant number of PWLD are reported to have behavioural problems that challenge services, behaviours often referred to as challenging behaviours. Challenging behaviours include: disruptive behaviours, non-compliance, self-injurious behaviours, aggression, destructiveness and over-activity (Lowe et al 2007; Emerson 2001). These are often seen as part of the individual affected and associated with dangerousness and unpredictability thus threatening the safety of the public (Chan 2012). With such actual and

perceived behaviours, affected individuals are likely to have limited access to mainstream services, little use of community facilities and prone to maltreatment (Emerson 2001: 1994).

In general, having learning disabilities without the adequate support can decrease their chances of leading more independent lives. This is not only in terms of living on their own, but also in terms of having choice and control over the support they need for everyday functioning and having equal access to life opportunities (Office for Disability Issues 2008:11).

Factors Affecting Prevalence rates of PWLD in United Kingdom:

Learning disability is said to be among the most common form of disabilities (Holland 2011; Harris 2005) and based on the statistical bell curve normal distribution it is estimated that 2% of the population have learning disabilities (Snoyman and Aicken 2011; Emerson and Hatton 2008). The estimates by the Department of Health in 2001 suggested that there were about 1.2million people with moderate or mild learning disabilities and 210 000 people with severe learning disabilities in England (DoH 2001:15). But following the 2% statistical bell curve population distribution guidance stated above, Emerson and Hatton (2008:03) estimated a figure of 985 000 in their 2008 article. Recent figures by Papworth Trust (2011) and the Scottish Government (2012) estimate that there are about 1.5million PWLD in Britain, which is approximately 3 in every 100 people (Papworth 2011). According to the Scottish Government (2012) this figure is expected to rise by 14% between 2001 and 2021 mainly due to the on-going advances in science and technology linked to increased survival rate of those with complex and multiple disabilities, improved standard of living and higher life expectancy (Holland 2008:5; Cooper, Melville, Morrison 2004).

Holland (2011) points out that it has remained difficult to provide accurate data on prevalence rates and the total population of PWLD in the United Kingdom. This is problematic due to a number of factors. A major factor is the lack of an established systematic way of collecting such information nationally (Emerson 2008). The statistics used is predominantly administrative data, that is, information and records of PWLD known to local authorities and the services they use (Stuart et al 2015). The lack of data from surveys and other sources makes it difficult to account for those not known to Local Authorities and services. This also makes it impossible to check for the accuracy of the available data (WHO 2011).

Another most significant issue is related to the variation in the definition of learning disabilities used. From one end of the spectrum is data collected based only on the definition of impairment (physical and intellectual disabilities), while at the other end of the spectrum is data collected based on a complex set of criteria combining terms such as impairment, functioning and support services required (Harbour and Maulik 2010). In between is data based fundamentally on IQ and exclude the physical aspect of people's disabilities (Schalock et al 2007). This lack of a precise definition results in variations in who fits in the inclusion and exclusion criteria of what is learning disabilities, hence, affects prevalence rates (WHO 2011).

Prevalence rates of PWLD can also vary according to the data collection methods used. For example, WHO (2011) compared data that can be obtained from national censuses with that from a survey. A census gathers data about every member of the population and a survey collects data from a sample of a population. WHO (2011) noted that countries which rely on national censuses to collect such data will record lower rates of learning disabilities. This is mainly due to the fact that national censuses tend to incorporate few relevant disabilities questions and social functioning issues. On the other hand, surveys tend to produce higher prevalence rates due to the fact that they provide richer information through comprehensive questioning and further probing, in the case of interviews (WHO 2011).

Ward (2012) raises the issue of those with mild learning disabilities, many of whom the author believes are hidden from official recognition because they have not been diagnosed as having a learning disability. This is a view shared by Simley (2005) who points out that there are difficulties detecting those with mild PWLD in particular where their life experiences are positive and have not exposed their disabilities. The author highlights that many will only be identified when they develop additional problems such as mental illness or when in contact with criminal justice system.

While the highlighted problems suggest the need for a more standardised approach to collecting data at a national level, the available estimates still indicate the existence of a sizable population whose life needs cannot be ignored or taken for granted (Scottish Government 2013).

PERSPECTIVES AND OFFICIAL CLASSIFICATION

Over many years, perceptions towards PWLD have varied significantly between practitioners, academics and communities (Munyi 2012; Schalock et al 2007). Munyi (2012) and Bray (2003)

highlighted that how we perceive people with disabilities is reflected in the way we treat them and impacts on the role they can play in society. Hence, an understanding of these variations in perspectives should help us draw out the controversy over the definition of PWLD. From the literature reviewed, three main perspectives have been identified namely: Clinical, Intellectual and Social perspectives.

Clinical Perspective:

The clinical perspective of learning disabilities, the dominant paradigm, is based on the medical model which emphasises symptoms and clinical syndromes (Schalock et al 2007; Mercer 1973) and the role of illness and impairment (Bury 2000; Williams 1999). Learning disabilities is therefore defined as a pathological condition which exists in the person affected and is understood through disease processes, heredity and biological abnormalities of the body. The symptoms or abnormalities can be diagnosed using standardised assessment techniques by clinically trained experts (Mercer 1973). In this perspective, the role of impairment in restricting activity is paramount and the social perspective is criticised for partially accepting or wholly rejecting the significance of bodily abnormalities in causing and defining disability (Thomas 2004). While some authors such as Bury (2000) and Williams (1999) believe in the roles of both bodily impairments and social exclusion in causing disability, they maintain the position that impairments are far more important in defining disability and reject the notion of oppression. But this approach may be criticised for ignoring or giving little importance to social factors, which some authors believe can contribute to the aetiology of learning disabilities. As Snoyman and Aicken (2011) points out, factors such as the effects of poverty and social deprivation may account for some lowered IQ scores in PWLD. It has also been criticised for pathologising learning disabled people and acting as the main approach around which the oppression of PWLD has been centred (Trent 1994).

Psychological (Intellectual) Perspective:

The intellectual perspective focuses on intellectual functioning and defines learning disabilities in terms of intelligence quotient (IQ) based on the assumption that human intelligence is a single entity that is measurable (Harris 2005). Intellectual functioning can be defined as the “spontaneous application of thinking and problem solving strategies as well as volitional control of their application to everyday situations” (Falconer 2007:3). In this process, intellectual functioning of the individual is measured using several standardised intelligence tests to obtain an IQ score (Scharlock et al 2007:119). Input by others and obtained from different settings is

necessary in order to make more valid conclusions (Falconer 2007:2). Individuals with IQ scores of below 70 are considered to have learning disabilities. PWLD are then further sub-classified within this range of up to 70 into mild learning disabilities (50-70), moderate learning disabilities (36-49), severe (20-35) and profound learning disabilities (below 20) (Whitaker 2008; Rittey 2003; Department of Health 2001; WHO 1996).

But critics point out that the use of IQ tests is not straightforward and can be problematic. Questioning the accuracy of IQ tests in measuring intelligence, Machek (2004) highlights that tests are not adequately informed by sound theory of how the brain works and hence there is no certainty that the actual intelligence has been accurately measured. The author further argues that the range of abilities assessed is narrow and there is the tendency to neglect other strengths of the individual being assessed. This is in line with Mortensen (2011) who criticises such tests for failing to fully consider other factors such as gender, race, class and culture, which add to the developmental complexities. Also problematic is the issue of rising of IQ scores over time. Flynn (1987) noted that IQ scores can change from one generation to another by between 5 and 20 points. As a result many people who would have been considered as having certain high IQ scores in the past generation might not be considered as having such scores in the next generations (Flynn 1987). Furthermore, Harris (2005:45) highlights that the effective use of these tests will depend heavily on the competence of the assessor and warns of the dangers of misapplications and misinterpretations of these tests.

Social Perspective:

The social perspective of PWLD is derived from the 'Social model of disability' which originated from the disability rights movement (Anastasiou and Kauffman 2011). The disability rights movement which calls for full citizenship, equal opportunities and equal civil rights emphasises on inclusion in society (Wallcraft 2003). The social model of disability developed and promoted by various theorists including Victor Finkelstein (1980, 2001) and Michael Oliver (1996), holds that the disability of people with impairments are a result of their exclusion from full participation in societal activities. Challenging the 'disability' as the umbrella term for all the disabling conditions endured by those with impairments, the model asserts that the physical and/or cognitive impairments should not necessarily lead to the application of such negative labels (Oliver 1996). In an attempt to counter the dominance of the clinical perspective and its limitations, the social model is applauded for adding the social aspect to the discourse and to have contributed to the significant improvements in the lives of disabled people (Thomas 2004).

Two main notions can be related to the social perspective of the concept of learning disabilities. The first notion perceives learning disabilities as a wholly socially imposed disability that amounts to a form of social oppression. According to this notion, the substance of disability is not situated in the person's impairments but on the society that places barriers which restrict social, political and economic participation (Finkelstein 2001; Oliver 1996). For Harris (2005:12), this becomes a form of impairment by others and for Galvin (2003) an imposed inferior social status that restricts full participation in society. The society is to blame and should be the one to reform its attitudes and actions towards PWLD and not the other way round (Thomas 2004; Finkelstein 2001; Oliver 1996). This perspective is criticised for totally ruling out the restrictions imposed by both physical and cognitive impairments as disabling (Williams 1999). Critics believe that positive changes in society's attitude alone will not eliminate the personal difficulties associated with having a physical or cognitive impairment (Thomas 2004).

The second notion is that which defines PWLD as having learning disabilities because of the restrictions by both impairments and society but view social oppression as the more significant cause of their disabilities compared to impairments (Thomas 2004; Shakespeare and Watson 2001). Here, there is acknowledgment that both impairments and social oppression (the dominant cause) have a role in causing disabilities, hence they cannot be seen in isolation. And by retaining the standpoint that disability is significantly defined by the social disadvantages and social exclusion, the emphasis remains on the need for accommodation from others and responsibility of society to provide support to help manage the needs of PWLD (Mental Health Special Interest Research Group 2001:05). While this notion considers both impairments and societal attitudes, critics disagree with the little emphasis on the role of impairments (Bury 2000; Williams 1999).

Official International Classifications/ Definitions of Learning Disabilities:

Each one of the above perspectives as stand-alone approaches will not be sufficient or adequate enough to form the basis on which to identify or diagnose learning disabilities. Hence, complex systems of sets of criteria have been developed borrowing from the positives of these historical approaches. This approach, which can be considered as the fourth perspective places emphasis on the support required to meet the life needs of the affected person. Commonly used systems of such criteria or classification of learning disabilities include: ICD-10 (WHO 1996), DSM-VTR (APA 2013, AAMR 2002) and ICF (WHO 2001).

The **ICD-10** is a manual produced by the World Health Organisation (WHO). The manual provides a complex multi-axial system to guide in the assessment, recording and diagnosing of LD (WHO 1996). The multi-axis system consists of five main axes which are considered necessary to record as follows:

- Axis I Severity of learning disabilities and problem behaviours
 - Axis II Associated medical conditions
 - Axis III Associated psychiatric disorders
 - Axis IV Global assessment of psychosocial disability
 - Axis V Associated abnormal psychosocial situations
- (WHO 1992, 1996)

The manual defines learning disabilities as a “A condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities” (WHO 1996:01). It delineates learning disabilities into five sub-categories namely mild (F70), moderate (F71), severe (F72), profound (73), other mental retardation (F78) and unspecified mental retardation (F79) (WHO 1992, 1996).

The **DSM-VTR** (2013) is a manual produced in the United States by the American Psychiatrist Association (APA 2013) to provide a standardised classification of Mental Disorders (APA 2000; Scharlock et al 2007). Like the **ICD-10**, it is a multi-axial system of assessment organised in the following five axes or dimensions for each psychiatric diagnosis:

- Axis I: Clinical Disorder
 - Axis II: Personality Disorders and Mental Retardation
 - Axis III: General Medical Conditions
 - Axis IV: Psychosocial and Environmental Problems
 - Axis V: Global Assessment of Functioning
- (APA 2000)

The classification manual defines learning disabilities as a ‘significantly sub-average intellectual functioning’ with: an IQ of approximately 70 or below, concurrent deficits or impairments in present adaptive functioning and onset before age of 18 years. It also classifies learning disabilities into sub-categories based on the level or severity of intellectual impairment namely:

Mild Mental Retardation (IQ level of 50– 55 to approximately 70), Moderate Mental Retardation (IQ level 35– 40 to 50– 55), Severe Mental Retardation (IQ level 20– 25 to 35– 40), Profound Mental Retardation (IQ level below 20 or 25) and Mental Retardation, Severity Unspecified (APA 2000).

The **AAMR (2002)** is another multidimensional classification system produced in the United States by American Association on Mental Retardation. According to Harris (2005) the **AAMR** approach differs from both of the **IC-10** and **DSM-IVTR** (now updated to DSM- VTR) in that it provides an expanded definition of intellectual disability that not only places emphasis on the individual's needs but also on and what can be done to improve functioning. The criteria to fit into this definition are based on the following five assumptions:

- Limitations in present functioning must be considered within the context of community environments typical of the individual's age, peers and culture.
- Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors
- Within an individual, limitations often co-exist with strengths.
- An important purpose of describing limitations is to develop a profile of needed supports
- With appropriate personalised supports over a sustained period, the life functioning of the person with mental retardation will improve

(Luckasson et al 2002:1).

Assessment is not limited to intellectual and adaptive skills impairments and other dimensions as psychological/emotional, physical health/etiological and environmental factors are considered too (Hawkins Shepard 1994). The AAMR (2002) manual defines learning disabilities as:

“Substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: Communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before the age of 18”.

International Classification of Functioning (ICF), Disability and Health (WHO 2001) intends to compliment the **ICD-10** manual. The **ICD-10** classifies disease (including learning disabilities) and the ICF describes and measures health and disability. The classification emphasises on how

people live considering mental and physical functioning, participation in activities of daily living and environmental factors. This aims to examine the various dimensions that impact on people's abilities to lead healthy lives and how these can be improved. It is perceived as a link between the medical and social models of learning disabilities that allows a more bio-psychosocial approach to meeting the needs of the individual at different levels, that is: biological, individual and social (Harris 2005:117).

LABELLING: BENEFITS AND NEGATIVE CONSEQUENCES

Contested Use of Labels:

Historically, PWLD have been known by many names or labels and the terminology of what is now referred to as learning disabilities in the UK has varied over the last 200 years (Mercer 1992; Goodey 2005). Through different generations and at different points in history they have received various labels which reflected a range of beliefs and negative attitudes held by the society (Atherton 2005). Such labels included: subhuman organism, unspeakable object of dread, menace, objects of pity, diseased organism, objects of ridicule, (Wolfenberger 1972), feeble-mindedness, mental deficiency, mental disability, mental sub-normality, mental handicap (Goodey, 2005; Mercer, 1992) and idiots (Atherton 2005). In addition, PWLD were associated with lunacy, criminality, witchcraft, mental illness (Atherton 2005:41). It was only in 1913 that PWLD were perceived as a distinct group from mental-illness where the Mental Deficiency Act 1913 classified mental deficiency into four types namely: idiot, imbecile, feeble-minded and moral defectives. In 1959 a new term "Mental sub-normality" was introduced to further make a distinction between learning disabilities and mental-illness (Atherton 2005:42). In 1980, mental sub-normality was substituted by the term Mental handicap which became the preferred label for PWLD (A Royal Albert Hospital Archives n.d) and later in 1990 the DH adopted learning disabilities as the official term to replace mental handicap in an endeavour to foster a more positive image of PWLD (A Royal Albert Hospital Archives (n.d); Bristol Public Health 2010).

In addition to having a historical variation, the terminology of what is learning disabilities in the UK is known by different names in other countries. These terms or labels include mental retardation, intellectual disabilities, developmental disability and mental disabilities. Others have continued to use the terms mental deficiency, mental sub-normality and mental handicap (WHO 2007). According the WHO (2007) most countries use mental retardation (76%) and intellectual disabilities (56%) and a lower percentage of about 32% of countries studied use the terminology learning disabilities. But the recent (2010) change by the United States of America in replacing

the use of “mental retardation” by “intellectual disabilities” may alter the percentage ratings mentioned. While the terminology used changed over time and varies across countries, Scharlock et al (2007) observed that the different terms used were attempts to label or define the same set of condition affecting and unique to PWLD. A set of conditions associated with physical abnormalities, childhood developmental delays and significant limitations in intellectual and functioning abilities (Mental Health Special Interest Research Group 2001). While effort was being made to present PWLD in a more positive light, the concept behind the labels remained unchanged that the new labels maintained the negative connotations in the older definitions they replaced (Galvin 2003).

The Benefits of Labels:

While there are negative consequences associated with the use of diagnostic labels, many scholars believe that they also offer considerable benefits (Blum and Bakken 2010; Boyle 2013). Based on the literature reviewed, the benefits of labelling PWLD can be recognised at individual and family level, professional level, and at local authority and national level.

At individual and family level, diagnostic labels help affected individuals and their families to know what the problem is. This can open doors for resources, opportunities and specific interventions otherwise not gained if the affected person did not have the label (Lauchlan and Boyle 2007). Also, knowing what the problem is can help PWLD understand themselves and make sense of the world around them including people’s attitudes towards them (Schalock et al 2007). Furthermore, this can help protect the affected learning disabled person from self-blame and from the general population as the public can be more tolerant of behaviours of people with labels compared to those without (Lauchlan and Boyle 2007). Parents may have explanations of what is happening in the family genetically and a label or explanation can help remove the blame from them (Richards 2011).

At professional level, the use of labels can help reduce ambiguities and provide the means to present the often complex information in a simplified manner. They aid professional communication and exchange of information using a shared terminology or language (Boyle 2013). Also, labels provide professionals with opportunities to focus on a particular problem in contributing towards raising awareness and continuity in advancing our understanding of the problems and behaviours affecting PWLD. This focus can be in the form of research, education and specialisation (Garand et al 2009; Boyle 2013).

At Local Authority and National level, the use of labels is essential for statistics and planning purposes (WHO 2011). They help to estimate the size of PWLD population, identify changes in their needs and to put in place relevant resources required to deal with their demands [education, housing, transport, learning disabilities related professionals and services] (Emerson 2008). The funding system is needs driven and the label is the criteria without which it will become difficult to acquire the resources needed to meet needs of affected PWLD (Boyle 2013). This is relevant considering the current estimates that indicate increasing population of PWLD with many surviving into old age and complex needs (The Scottish Government 2013).

In conclusion, Ruscio (2004) believes that the benefits of labels cannot be underestimated. According to the author, much attention has been given to literature on the stigmatising impact of labels on PWLD and not much credence given to literature on these benefits. Hence considering the many benefits mentioned above, Boyle highlights that the debate on labels should not be simply about whether they are good or bad as this will fail to address the complicated nature of their original intended use (Boyle 2013).

The Negative Consequence of the Label Learning Disability:

But critics highlight the negative impact of such labels. In general, labels are perceived as stigmatising and re-enforcers of negative treatment (Goffman 1961). In line with this view and more specific to learning disabilities, Atherton (2005:39) suggests that the label learning disabilities can affect the treatment they receive and the general quality of their life. This is likely to be the case where learning disabilities is perceived as a state of complete incompetence (Hawkins- Shepard 1994) that will be associated with an inability to function and an inability to adapt (Baroff and Olley 1999). According to Baroff and Olley (1999:09), below average intelligence does not necessarily mean an inability to function in all areas of daily life and that 'difficulties in understanding complex information and failing to excel in academic skills does not always prevent people from achieving adaptations that enable independent living'. Therefore, the focus on inability is seen as flawed.

Another problem with the label or diagnosis of learning disabilities is the issue of diagnostic overshadowing raised by Cooray and Bakala (2005) and Sovner (1986). This is when the presenting signs and symptoms of ill-health as well as the other frustrations in life are incorrectly attributed to having a learning disabilities (Cooray and Bakala 2005; Sovner (1986). As a

consequence, other potential causes and alternative treatments or support will not be timely sought. Closely related to the diagnostic shadowing problem is the difficulty of self-fulfilling prophecy. Once diagnosis of learning disabilities is confirmed, there is the anticipation that certain behaviours or characteristics will occur and this can lead to the promotion of these anticipated behaviours or characteristics (O'Brien 2006). Furthermore, the whole notion of labelling or diagnosing as learning disabilities can encourage therapeutic nihilism where people take the view that learning disabilities is unchangeable and therefore nothing much can be done to improve the situation of PWLD (Turk 2007; O'Brien 2006).

The definition, perspectives and official classification are relevant to this study because of their link to labelling, stigma and in turn oppression. Despite replacing the unpleasant labels with more acceptable ones and the efforts to move towards a more integrated classification of learning disabilities, PWLD have remained among the most stigmatised group in the society (Ali et al 2012). The new label, learning disabilities, has maintained the stigmatising and oppressive connotations from the labels it has replaced. Hence, continuing to pathologise PWLD means retaining the use of labels which in turn 'spoils' a person's identity so that the need for help and treatment are the most dominant characteristics of their lives. This negative perception in turn leads to notions of social control, which is to be exercised not only by practitioners, but also carers and the wider community. It is within this complex mix of having a 'spoilt identity' (Goffman (1963) that oppressive practices emerge. According to Goffman (1963) in the 'Spoilt identity' mix, the stigmatised PWLD are not seen as normal and are not fully accepted by society. As a long term strategy, they try to cope with their rejection through constantly adjusting their identity to fit with how they are perceived.

CONCLUSIONS AND REVELANCE TO CURRENT RESEARCH:

Although the definition of learning disability reflects the changing knowledge and societal responses to PWLD, it continues to have its controversies in terms of its ability to allay the fundamental problem of difference and aid to the full acceptance of PWLD by society. While this has been a more accepted term compared to previous labels such as idiot, imbeciles and feeble-minded, it is important to recognise that 'learning disabilities' is an umbrella term that defines a heterogeneous group and it should not be assumed that everyone's difficulties and life experiences are the same or uniform. On this note, it is worth highlighting from the outset that this study used a sample of people with moderate to mild learning disabilities whose needs may be different from those with severe to profound learning disabilities. However, findings may

still be transferrable to the life experiences of people with severe to profound learning disabilities.

CHAPTER 2: DEFINITION OF OPPRESSION

INTRODUCTION:

There exists plenty of evidence to suggest that throughout history the lives of PWLD have often been characterised by experiences of oppression (Atherton 2005). However, while the meaning of the term 'oppression' may seem intuitively obvious, both scholars and practitioners continue to experience difficulties when attempting to develop a useful definition for the purposes of doing research. This chapter attempts to draw together and try to make sense of some of these definitional difficulties. The chapter is divided into 3 sections. Section 1 provides a generic definition of oppression and highlights the complexity of its concepts. Section 2 attempts to classify some of the main meanings of oppression in terms of some of the key components of the concept and Section 3 will detail some important social and emotional consequences that may arise from experiences of oppression.

To retrieve literature for definition of oppression in this chapter, the following databases were searched: PsycINFO, ESBOD and CINHALL. Vital information was also obtained from google scholarly articles, books and journals. All searches used key words such as: Oppression, Suppression, Maltreatment, Domination, Injustice, Concept and Definition

OPPRESSION AS A COMPLEX CONCEPT:

Oppression is a complex, multi-faceted and dynamic concept that covers diverse forms of systematic and harm inflicted to one social group by another group or by the state (Frye 1983; Cudd 2006). At the heart of the concept is an on-going endeavour by various authors to highlight the deep social inequalities and the essential differences in life experiences between the dominant and the dominated social groups in society (Abberley 1989). One such author is Frye (1983) who equates the experience of being oppressed to that of being in a cage where one's movements are restricted by barriers and forces (put in place by the oppressor), which are not accidental or occasional, but are systematically related to each other. Similarly, others including Young (1990), Harvey (1999, 2010), Sensoy and Diangelo (2009) and Cudd (2006) talk about the interactions that occur between policies, practices, norms and traditions and how they intersect to systematically exploit the targeted weaker group(s) in society. Taking this further, Collins (2000) uses as an example the mal-treatment of black women in the USA to illustrate how the targeted groups can suffer multiple oppressions. In the case of these black women, they are not only 'gendered' but also 'raced' and classed according to other identities related to their sexual orientation, religion, age and disability (Hardiman and Jackson 1997: 21).

Pierce (2012:29) suggests that the concept is further problematised by the lack of clarity regarding the distinction between oppression and immoral acts in general, whereby few examples differentiating the two are presented in the literature. Even more controversial, are the views by some authors suggesting that: not all forms of oppression can cause harm to the oppressed person/group's interests (Wertheimer and Zwolinski 2013); the oppressed may not be even aware of the harm caused to them (Harvey 2010, 1999); and that individuals or social groups can acquire a double role of being the oppressor and the oppressed at the same time (Harvey 2010; Cudd 2006). Such diverse views clearly demonstrate how the concept of 'oppression' is not as straightforward as it sometimes appears to be.

Here we have to be clear that it is not the existence of oppression which is being questioned but simply highlighting the challenges involved in trying to develop a definition that can be meaningfully used in research. The diverse views on oppression offer a broad spectrum of socially imposed negative life experiences and hardships affecting some groups. These can be used to understand, reflect on and try to improve the way we treat each other as human beings. This can be even more important when dealing with PWLD who already have impairments and whose oppressor is not pinned down to one dominant social group but to the society as a whole.

PERSPECTIVES OF OPPRESSION:

The general consensus in the literature reviewed is that oppression exists, though Robbins (2011) observes that the complex nature of this concept may in part originate from the fact that a wide range of disciplines continue to compete with one another in their attempt to establish its true meaning. Hence, different theorists and social philosophers have focused on specific concerns (Robbins 2011; Sidanius et al 1999) and specific aspects of oppression from which generalisations have been derived (Heldke and O'Connor 2004; Sidanius et al 1999). Such concerns include power and domination (Sensoy and Diangelo 2009; Sidanius et al 1999; Thompson 2003), privilege (Harvey 2000) and structural inequalities (Young 1999). Racism, classism and sexism (Hanna, Talley and Guindon 2000) are some of the frequently examined single aspects of oppression. In an attempt to generalise meanings from these diverse focuses, oppression has been categorised into three groups: a) oppression as a product of social dominance, b) oppression as a product of harm and coercion and c) oppression as a product of the civilising process.

Oppression as the Product of Social Dominance:

Several authors perceive domination as the term that can be used to sum up the processes involved in developing and maintaining inequality among social groups (Sidanius et al 1999; Cudd 2006; Thompson 2003). Social dominance theory by Sidanius et al (1999) asserts that societies are organised around intergroup oppression, discrimination and prejudice. It tends to form and maintain group based hierarchies with subsequent group inequalities. The stronger or dominant group(s) will then negatively exercise its powers to dominate the subordinate weaker groups economically, politically, culturally and socially (Weick (2001:261). In this case, a social group suffers hardships and injustice as a result of being in a state of subservience linked to the negative and degrading use of power by a dominant group (Thompson 2003:34). This can be in the form of one class versus another class, one gender against another, one race dominating the other or the non-disabled versus the disabled.

While the social dominance helps to understand some important sources of and social processes involved in the oppression between social groups, the theory has been criticised for portraying some form of determinism which justifies hierarchy and dominance of one group by another (Banaji and Nosek 2004). Such affirmation of the inevitability of dominance of weaker groups can mean that efforts to end the oppression of vulnerable social groups such as PWLD will be a

vain attempt. The endeavours to make the necessary changes in attitudes towards PWLD and the removal of social and economic barriers that impede their full participation in society are made difficult by this orthodoxy approach to understanding oppression. In other words, this can be interpreted as making some indirect justifications for maintaining PWLD at the bottom of the social ladder which in turn can predispose them to all kinds of oppressive experiences (Oliver 2012).

Oppression as the Product of Harm and Coercion:

This standpoint of oppression is generally based on the work of Cudd (1994, 2006, 2013). While the author considers the domination of one social group by another and the role of structural forces in causing oppression, the author believes that systematic forms of harm and coercion are key defining characteristics of this social phenomenon. However, Cudd (1994, 2006) acknowledges that all of the characteristics that may constitute oppression cannot be captured in these two components alone. The author suggests the following set of four elements which when combined together should constitute oppression:

1. Oppression must involve some kind of harm [but not all harm is oppression (Cudd 1994:25)]
2. Oppression must include some form of coercion or force (physical or psychological)
3. The oppressed group suffers harm, due to its membership to that particular group, inflicted by another social group
4. The dominant oppressing group must benefit from oppressing other groups (Cudd 2006, 1994)

However, these criteria may be criticised for not providing a comprehensive explanation of the challenges involved in defining or identifying the specific types of social harm that are or are not oppressive. This is particularly important in situations where harm caused is unobservable or unnoticed by the oppressed or by both the oppressed and oppressor (Harvey 2010, 1999). An example is the case of exploitation of PWLD by people who come as friends to take advantage of their benefits money. Such explanations are also important in the light of comments by Wertheimer and Zwolinski (2013) that not all forms of exploitative experiences always cause harm to the interests of the exploited. In trying to separate oppressive harm from non-oppressive harm, there is a danger of neglecting the non-oppressive harm which may even have more serious effects upon the lives of individuals or groups (Hillyard et al 2004). In addition, if oppression is about harm inflicted by one social group to another, this ignores the complexity of

oppression within groups, for example where some PWLD suffer oppression from other PWLD (Fyson 2007). Furthermore, this definition does not expand on how the oppressors benefit from oppressing others. This was made even more complex by Wertheimer and Zwolinski's (2013) assertion that the exploited individual or group can at times also benefit from their exploitation.

Oppression as the Product of Social-Structural Forces:

There is overwhelming support for the view that oppression is a product of a confluence of social structural forces that cause systematic harm to the individual or a social group. The various social institutions including the family, education, industry, religion, politics, law and public services are said to be organised and managed in ways that connect to determine or influence life opportunities of targeted social groups (Harvey 2010; Young 1990; Bell 1997). The discrimination and social exclusion of people from specific groups such as black and ethnic minorities, homosexuals, women and the disabled is widespread in social institutions and entrenched in individuals (Collins 2000; Bell 1997). As a result of this complexity many authors tend to focus their attention on single aspects of oppression such as racism (Lowe, Okubo and Reily 2012; Alexander 2005; Adams and Sanders 2003), sexism (Albertyn 2011; Korpi 2010; Ahmad and Bhugra 2010), homophobia (Gasparini and Wintemute 2012; Green 2002) or specific disabilities (Watermeyer 2012; Oliver 1996). While the benefits of looking at a single aspect would increase knowledge of these issues, the difficulty arises when generalisations about oppression are based on the single aspects. According to Hanna, Talley and Guindon (2000) limiting oppression to an individual aspect will only aid to a simplistic conceptualisation of the term and hence offering a distorted picture of the intricacies involved in oppression in general.

Supporting the social-structural cause of oppression and moving away from a single aspect approach, Katz (1978) suggested a classification according to individual, institutional and cultural oppression. The author states that the three levels or dimensions interact with and reinforce each other to introduce a complex web of processes of oppression. At individual level the focus is on the beliefs, attitudes and behaviours of the individual. At institutional level, this involves the application of institutional policies and procedures that collude with a social oppression to produce oppressive consequences for example unequal treatment of PWLD by the criminal justice system or unequal access to education by PWLD. At a societal/cultural level: cultural norms perpetuate the values that bind the institutions and individuals. The cultural perspectives of the dominant groups are imposed by institutions upon individuals for example

the culture of the medical model see PWLD as sick and needing to be cared for by others. See figure 1 for further examples of the levels and types of oppression.

Table 1: Levels and Types of Oppression
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From Judith H. Katz (1978). *White Awareness: Handbook for Anti-Racism Training*. Norman, OK: University of Oklahoma Press

Integrating both single aspects and the three levels of oppression suggested by Katz (1978) above, Bell (1997: 4-5) proposed a set of six criteria below which combined together should constitute oppression:

1. Pervasiveness: Oppression is the pervasive nature of social inequality woven throughout social institutions as well as embedded within individual consciousness. For example, PWLD experience discrimination
2. Restricting: Oppression represents structural and material constraints that significantly shape a person's life chances and sense of possibility.
3. Hierarchical: Oppression signifies a hierarchical relationship in which dominant or privileged groups benefit, often in unconscious ways, from the disempowerment of subordinated or targeted groups. For example, the practitioner / service user with learning disability relationship.
4. Complex, Multiple, Cross-Cutting Relationships: Power and privilege are relative, as individuals hold multiple and cross-cutting social group memberships.
5. Internalized: Oppressive beliefs are internalized by victims as well as benefactors.
6. "Isms": Shared and Distinctive Characteristics: Oppression is manifested through racism, sexism, classism, anti-Semitism, ableism, and heterosexism and the dimensions of experience that connect "isms" in an overarching system of domination. For example, ableism as a form of prejudice or discrimination against PWLD.

While agreeing with the social structural perspective to oppression, Young (1990) argues that different groups are not oppressed to the same extent or in the same ways. For this reason, Young argues that categorising all that constitutes oppression based on oppressive experiences within particular groups or based on single concerns, such as race, may miss the common experience of oppression across groups. Hence, the author suggests that in order to avoid a reductionist approach that can exclude several oppressed groups, oppression can be best defined by how the various groups experience it (for example marginalisation, exploitation and violence). This approach is in agreement with the ideas by Abberley (1987) who suggested the use of oppression theory as a means to best able capture the inequalities faced by PWLD in UK. This is also in line with Northway (1997), building on Young's (1990) five types of oppression, suggested a sixth type: 'Discrimination'. The author believes that discrimination (unequal and differential treatment) is a separate entity of oppression which is distinct from marginalisation. Unequal and differential treatment is what many PWLD regularly experience and hence, discrimination is a major form of their oppression which needs the necessary attention it deserves.

Oppression as the Product of Civilising Process:

The perception of oppression as a product of civilising process is recent and reflects the dynamic character of the concept (Harvey 2010, 1999; Young 1990). Cudd (2006) noted the concept of oppression has shifted over the years from a purely political conception of oppression (where the ruler or state is the oppressor and the ruled being the oppressed) to a more social conception of oppression where the oppressor and oppressed are both social groups. Young (1990) noted this shift too and emphasised that oppression is not simply an exercise of brutal tyranny in non-democratic nations. She points out that the new meaning, introduced by the left wing social movements of the 1960s and 70s, denotes that oppression is the experience of disadvantages and injustice imbedded in everyday practices of a liberal society. It is not simply a matter of one group being superior over another or a consequence of random individuals' policies, actions of violence or discrimination.

“.. the vast and deep injustices some groups suffer as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions that are supported by the media and cultural stereotypes as well as by the structural features of bureaucratic hierarchies and market mechanisms” (Young 1990: 41).

This new meaning is what Harvey (2010; 1999) coined as ‘Civilised oppression’. According to the author, these subtle means of oppression do not rely on physical violence or the use of law to oppress. The harm inflicted is not always observable or tangible and that it is difficult for the oppressed to be aware of the oppressor’s intentions or acts of injustice. By inflicting harm systematically but in a lesser brutal manner, the pain is thinly spread and hence not felt compared to when direct acts of violence are applied. In some cases, even the oppressors may not be aware of their oppressive behaviours (Harvey 2010, 1999). Despite the lack of visibility of the tools at work, the processes involved nevertheless contribute to some of the observable harm such as poverty, unemployment and lack of other opportunities (Harvey 2000). This is not the kind of oppression which can be eliminated by removing rulers or changing laws (Deutch 2005), but it is embedded in and applied by individuals, social groups and institutions in ways that present as the everyday norm (Harvey 2010, 1999; Young 1990).

For Harvey (1999), the biggest challenge we face is to be aware of and understand these new subtle ways of oppression which the author states have become the most prevalent in the western world. In this endeavour, Harvey (1999) identified several key principles believed to underpin the nature of civilised oppression. At the heart of civilised oppression is the distorted and morally unsound relationships between those who do not share the same social status or power privileges (Harvey 2000). It is through these distorted relationships that individuals or groups of people are blocked or denied the exercise of certain basic moral rights, socially excluded, isolated and undergo what she termed “moral subordination” (distortion of basic relationships). Moral subordination becomes a fundamental component of civilised oppression and the differences in power and status predispose the oppressed to such an unfair position (Harvey 2000).

In their study of individuals and families with chronic obesity, Rogge, Greenwald and Golden (2004) summarises the principles or characteristics of Harvey’s (1999) civilised oppression into the following six categories:

- 1) **Non-peer, power-laden relationships:** Non-peer power-laden relationship is seen as a prerequisite for the existence of civilised oppression. The relationship between the individuals has to be unequal based on personal power derived from attributes such as wealth, education, position of authority within organisations, social prestige or social position;

2) **Interactions that diminish and control the recipient who has little recourse:** The oppressed individual or social groups have no choice but to become involved in relationships with their oppressors. The relationships are generally not positive and are loaded with interactions that belittle, diminish, degrade, and control the oppressed person; for example the abusive relationship between PWLD and their carers at the Winterbourne View hospital as shown in the BBC documentary in 2010.

3) **Cumulative acts of omission and commission that distort the relationship:** Civilised oppression involves cumulative series of trivial acts that distort relationships. These acts may not be observable or tangible which may require, on behalf of the oppressed, skills, knowledge and time to realise that oppression was taking place. The oppressed individual or social group may end up entangled in numerous problems that can affect multiple areas of their lives. The oppressed individuals will perceive these problems as products of their everyday living and not products of experiences of oppression.

4) **Harm or disadvantage accrue:** The harm or disadvantage in civilised oppression tends to accumulate mainly due to the subtleness of the types of oppression involved which delays identification of the problems. The harm or disadvantage will vary in terms of degree of severity and visibility. This can include humiliation, isolation and economic disadvantages.

5) **No malicious intent:** Civilised oppression takes place even where it was not the intention of the oppressor to inflict harm. Well-intentioned acts that reinforce power difference or inequalities that cause harm to the victims can contribute to oppression. In this case, the perpetrators may not be aware of the harm they have inflicted on individuals or social groups.

6) **Insidious and obscured in routine or daily encounters:** The harm or disadvantage that accrues come masked and manifest as the norm. The emphasis by Harvey (2010, 1999) is that without physical violence and apparent use of the law to oppress, victims are unlikely to be aware of their oppression. This becomes even more relevant among PWLD who have cognitive impairments that can increase their susceptibility to entering into these distorted relationships which in turn can cause their life-long oppression. Hence, Harvey (2012, 1999) points out that the main challenge here is to be aware of this prevalent form of oppression and to understand how it works in order to take the appropriate measures.

SOME KEY CONSEQUENCES OF OPPRESSION:

While they may not be clear cut and precise definition that embraces all what constitutes oppression (visible and hidden), the different theories and definitions discussed offer an in-depth understanding of the complexities involved in social relationships as well as the inequalities that can arise from them. It can be seen as the strength of the concept of oppression, its ability to make sense of the wide range of oppressive experiences affecting various social groups including PWLD.

Despite the differences in approaches of understanding this concept, the different authors and theorist agree that oppressive experiences can have far reaching consequences on the lives of those affected. The consequences can range from physical and psychological harm to poor quality of life. Based on Young's (1990) framework of oppression these have been generalised to those associated with marginalisation, powerlessness, exploitation and victimisation.

Marginalisation:

Young (1990) perceives marginalisation as the most dangerous of all the five faces of oppression. The author describes the process of marginalisation as one that excludes some social groups from community participation and restricts their political and economic contribution. As a consequence, the excluded subjects will have poor access to social systems such as health and education and little or no employment opportunities (Sagric et al 2007). In turn the targeted groups including the old, the physically and mentally disabled, ethnic minorities and women are likely to be subjected to poor living standards and material deprivation and as a result they are likely to end up relying on the welfare services to survive (Young 1990). This can then lead to an oppressive dependence where what is best for the marginalised group is determined by the welfare service providers. Young (1990) makes it clear that dependence itself is not the issue as people have to depend on each other. However, it becomes a problem when it is used as a platform on which to violate a whole population's right to equal citizenship and to deprive them respect, dignity and choice. One significant consequence of this imposed marginalised status is that it can have a detrimental effect on people's physical and mental well-being (Sagric et al 2007).

Powerlessness:

Powerlessness can be defined as the state of not being able to effectively influence actions or decisions about one's life events (Lord and Hutchison 1993; Keiffer 1984). This limited access to power and influence can be categorised into two types namely real and surplus powerlessness

(Lord and Hutchison 1993; Lerner 1986). Real powerlessness is a consequence of the role oppressive social forces play in diminishing the subject's power (Lord and Hutchison 1993; Lerner 1986). The existence of structured social environments (special needs schools, institutionalised forms of accommodation) that fail to adjust to the needs of and impose control over PWLD, are examples of some external forces that disempower such oppressed social groups (Oliver 2012). Consequently, the weakened or disempowered people, enter into a cycle of on-going dependence on those who control their lives, thus exposing themselves to greater domination and exploitation (Hamm and Smandych 2005; Fraser 2003).

Surplus powerlessness is a result of internal forces that develop a state of learned helplessness where the oppressed subject believes that there is little they can do to change their life situations (Lord and Hutchison 1993; Lerner 1986). They accept or internalise their oppression with some possible serious psychological problems that may include self-hate, self-blame, low self-esteem and a general lack of motivation to change the status quo (Pyke 2010; Lord and Hutchison 1993). For PWLD, internalising their oppression can lead to placing the blame on their impairments and not the external forces stated above (Lord and Hutchison 1993; Asch 1986). Overall, powerlessness will be restrictive in many areas such as choice, decision making, autonomy and self-determination (Pyke 2010) and only help to prolong oppression (Lord and Hutchison 1993).

Exploitation:

According to Young (1990) exploitation is a steady process of the transfer of the results of the labour of one social group to benefit another (Young 1990). This is based on Karl Marx's theory of exploitation in which he asserts that the control of the means of production by capitalists compels the workers to enter into an unfair wage-labourer contract. But Wertheimer and Zwolinski (2013) argue that exploitation comes in different forms and Marx's labour exploitation theory does not account for other forms of exploitation. After analysing 15 definitions of exploitation, the authors concluded that common to all the definitions was the general notion of "taking unfair advantage" of the other. The definitions focused on different issues ranging from coercion, lack of benefit by exploitee, to harm caused to the exploited with only a small number limiting the definition to the relationship between the rich and the poor. Young (1990) also acknowledged that exploitative oppressive phenomena occur in everyday and ordinary interactions at home, in public spaces and in institutions. In 'mate crime', for example,

those who exploit PWLD pretend to be friends and these are usually ordinary local people known to the victim (Thomas 2011), not those in the capitalist social class. A study by Lemos and Crane (2012) reports experiences by PWLD of being taken advantage of emotionally with some promises for a relationship. The victims were left hurt on discovering that the perpetrators were only after their money and a place to stay.

Violence:

Young (1990:62) defines oppressive violence as the systemic use of threat, coercion and force directed at members of a certain group solely because of their affiliation to a targeted social group. In this case, PWLD will be targeted simply because they have a LD. As highlighted by Young (1990), the victims will be aware they are being targeted and become indirectly controlled by the fear of being violently victimized. The violence can be random or organised unprovoked attacks that aim to hurt, humiliate, intimidate, stigmatise, harass or in rare cases, even kill. Available evidence in the literature suggests that PWLD are more likely to endure oppressive violence over prolonged periods of time compared to the general population. A study by Mencap (1999) found that 90% of PWLD experienced some form of harassment and bullying in their everyday lives. A recent study, on behalf of the Equality and Human Rights Commission by Sin et al (2009), show that PWLD are at a higher risk of being victims of targeted violence and hostility. They are particularly at an increased risk of experiencing sexual violence and becoming victims of anti-social behaviours. In other revelations damage to property, hate crime and even murder have been reported (Disability Now 2013, Stephenson 2009). From these examples one can tell that violence remains an important way of keeping certain social groups in positions of inferiority. These issues will be more thoroughly discussed in chapter four.

CONCLUSION AND RELEVANCE TO THE STUDY:

Oppression is a complex and multi-faceted concept attempting to define a wide array of acts of systematic suffering inflicted to individuals and social groups by other human beings. It is the strength of this concept in being able to capture the essential aspects of the nature, possible causes and impact of oppressive experiences affecting individuals or specific social groups that it was very relevant to this study. As pointed out by Abberley (1987), capturing these essential aspects of oppression should not only help to highlight the social inequalities affecting PWLD but also help to understand the bigger picture of the problems this social group face in their daily lives. Hence, drawn out from understanding of the literature and themes emerging from data

collected, Marginalisation and Victimization were the major forms of oppression identified which will be critically analysed in chapters 3 and 4 respectively.

CHAPTER 3: MARGINALISATION OF PEOPLE WITH LEARNING DISABILITIES

INTRODUCTION:

The aim of this chapter is to critically review key research findings on marginalisation experiences affecting PWLD. The goal is to synthesise the current state of knowledge related to the social difficulties PWLD face, in the process identifying gaps in previous studies and where this study fits into the existing body of knowledge. This review is important because, while a great deal of work has been carried out to highlight the marginalisation status of PWLD (Hall 2004), very few empirical studies have looked at marginalisation as the primary focus and rarely has this been explored in terms of oppression.

THE LITERATURE REVIEW PROCESS:

The literature search was carried out between January 2012 and March 2015. The most relevant databases covered literature within sociology and nursing and included: databases PsycINFO, Medline, ESOB and CINAHL. Internet searches for online literature and relevant websites were carried out using Google and Google Scholarly search engines. Other sources of relevant information were obtained from non-electronic sources such as book catalogues, and article reference lists. Grey literature including commissioned reports, unpublished material and organisational project papers and guidelines were also considered. Table 2 presents an overview of the key search terms used relevant to the subject area of interest. These terms included the main concepts; Learning disabilities and Marginalisation. Intellectual disabilities and mental retardation were used as synonyms for learning disabilities. Social exclusion, exclusion, social, economic, unemployment and underclass were used as synonyms and/or variations for marginalisation. All the key words within the database search were located in abstracts only.

TABLE 2: Marginalisation Literature Review Search Terms

Concepts	Variation/Synonym	Location
Learning disabilities	Intellectual disabilities Mental retardation	All abstracts only
Marginalisation	Social exclusion Exclusion Social Economic Unemployment Underclass	All abstracts only

Inclusion and Exclusion Criteria:

Table 2 highlights the inclusion and exclusion criteria used in this literature review. While there is evidence that people with disabilities in general are subjected to experiences of marginalisation in their daily lives, the emphasis of this research is on PWLD. Studies which investigate experiences of children and/ or adults with learning disabilities have been included to reflect on the close association of their difficulties in childhood and adulthood (Heslop and Abbott (2009)). The studies included in this search are from 1990 onwards. This reflects the limited number of primary research studies in this area (Hall 2004). Hence, studies outside UK should help capture some primary studies done elsewhere from which new ideas can be developed. Also, evidence from literature reviews and cases series or case studies will be included considering this limitation in primary studies.

Table 3: Marginalisation Literature Review Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Time Frame	1990 onwards	Before 1990
Language	English only	Non-English
Population	Involving children and/ or adults with LD	Focus on other disabilities only
Geography	UK, Europe, Americas, Africa and Asia	
Types of study	Primary research and secondary research studies, Literature reviews, case series/studies and commissioned reports.	Editorial articles Anecdotal stories Commentaries

Search Process and Outputs:

In total 501 articles were identified, of which 234 were duplicates. Further screening resulted in 74 to be considered in line with the inclusion and exclusion criteria. Of these 39 records were excluded as not relevant. The full text for 45 articles were reviewed and a further 14 were excluded as editorial articles and other commentaries. This resulted in 31 relevant studies which satisfied the reviews inclusion criteria. A further 6 studies which met the review inclusion criteria were obtained from additional sources such as hard copy and grey literature searches. A total 37 of relevant articles were retained that cover the different forms of marginalisation experiences affecting PWLD.

Guidance from critical appraisal skills programme (CASP) checklist was used to assess the quality of the 37 articles. This was considered suitable for the current review because it can be applied to both quantitative and qualitative research methodologies. For each paper was rated as being good if it fully met the criterion set in the checklist, satisfactory if criteria is met partially and poor if not sufficiently met. From this process it was observed that studies included a mixture of quantitative, qualitative and mixed methods research that were assessed separately. Quantitative studies make the majority of the studies and a very small number are mixed methods research. Very few of these are primary studies and have paid attention at marginalisation as the principal focus.

This chapter will be structured around five sections based on the themes emerging from this literature view. Section 1 provides some definitions of the term marginalisation; Section 2 examines the problem of societal negative attitudes and the role they play in facilitating marginalisation of PWLD; Section 3 looks at how PWLD are socially marginalised with a focus on social relationships, community participation and human rights; and Section 4 reviews literature on the economic marginalisation of PWLD highlighting the nature of the problem

including the barriers that hinder their economic participation. It will also briefly consider the notion of underclass.

DEFINITION OF MARGINALISATION:

UNESCO (2000), in its consultative forum for 'Education for All,' stipulated that "marginalisation occurs when people are systematically excluded from meaningful participation in economic, social, political, cultural and other forms of human activity in their community and thus denied opportunity to fulfil themselves as human beings". This definition is highly significant because it emphasises the key forms of marginalisation that are to be discussed throughout the rest of this chapter.

More broadly, marginalisation can be defined as the exclusion from mainstream society of those who are not widely accepted by the most dominant social, economic and political groups (Vasas 2005; Hall et al 1994)). In her framework of analysing oppression, Young (1990) identified marginalisation as the single largest form of oppression which can affect any oppressed social group. Similarly, Burton and Kagan (2003) suggest that this is a multi-layered concept that involves: 1) the marginalisation of a wide range of people/groups on the basis of their age, gender, ethnicity, sexual orientation, mental health and 2) the marginalisation of those who occupy a wide range of unconventional social roles and responsibilities such as family, community leaders and political figures. Furthermore, it should not be seen as only a phenomenon of Third World countries but also as a phenomenon of the Developed World (Jenson 2000; Young 1990). Hence, it should be understood beyond economic factors like poverty to include other forms of oppression such as being denied access to social rights, knowledge and power (Jenson 2000).

NEGATIVE ATTITUDES TOWARDS PEOPLE WITH LEARNING DISABILITIES:

A review of the literature has shown that PWLD have a long history of being perceived negatively. A clear association between these negative perceptions and their personal experiences has been highlighted by various authors. They were seen as immoral, mentally ill and as a danger to society that they were frequently managed through institutionalisation. Living conditions in these institutions were deplorable and the care they received was inadequate (Walmsley 2005; Atherton 2005). In the 1970s leading to the closure of big institutions, it was hoped that society's attitude would gradually enlighten and eventually transform. But a recent study by MENCAP (1999) revealed that negative attitudes remain widespread and entrenched throughout society. Similarly, Walmsley (2005), points out that community living has not done

much to encourage the fundamental change in social attitudes, consequently negative attitudes towards PWLD have continued to persist within society. According to Hannon and Clift (2010), the society's negative attitudes towards PWLD can be defined as the major barrier between PWLD and everyday living life opportunities.

Other research studies support the claim of widespread negative attitudes towards PWLD and the barriers they introduce in their lives. One such example is a UK study by Staniland (2010) on behalf of the Office for Disability Issues which measured public attitudes towards the disabled people including PWLD between 2005 and 2009. While the study reported some improvements in public attitudes towards the disabled and disability since 2005, it concluded that PWLD are more likely to encounter prejudice from the public compared to other disabled people without LD. Most of the members of the public who participated in the study preferred to interact with those with physical or sensory impairments rather than with PWLD. They also perceived PWLD as less productive and lacking in leadership qualities as a result they were not happy to have PWLD as their member of parliament. On the whole, interviewees believed that prejudice against PWLD is widespread and they felt that the society's negative attitudes towards them play an important role in their marginalisation.

A recent systematic review of the literature by Scior and Scior (2011) confirms some of Staniland's (2010) findings. The review which investigated the public awareness, attitudes and beliefs towards PWLD in various countries, affirms that PWLD are consistently regarded as the least desirable social group that members of the public would like to interact with. Public behaviours towards them are more negative compared to those with physical disabilities. Also, the review was able to identify that there are some links between the negative societal attitudes and the misconceptions it has about learning disabilities in terms of what it entails, its causes and its prevalence. Importantly, the study noted that the negative perceptions derived from these misconceptions are not always as a result of hostile attitudes towards PWLD. At times they can be from sincere beliefs that PWLD would not benefit from some forms of inclusion such as education in mainstream schools.

Despite the usefulness of studies reviewed in the systematic review, Scior and Scior (2011) is critical of much of the previous research literature in this area. The author highlighted significant methodological limitations including: the lack of longitudinal studies which would help with measuring and explaining stability and change over a prolonged period of time (Schuller 2012);

use of small samples which are a problem because they may not be able to uncover the important issues related to the research question (Manson 2010); and the dominance of descriptive accounts of attitudes which fail to capture the complexities involved between the relationship attitudes, stigma and social exclusion. The author also observed that there is still scarce literature on policies that can help confront issues of negative attitudes and specifically the problem of misconception. And as noted by the organisation Turning Point (2004), members of the public are not under any pressure to change their attitudes towards this vulnerable group.

Some studies have investigated attitudes of professionals toward PWLD. This has shown that negative attitudes towards PWLD are not only endemic to the general population but also prevail among professionals. For instance, Slevin and Sine (2006), in comparing negative attitudes towards PWLD among graduate and non-graduate nurses, found that both samples were more negative than would be expected from healthcare professionals. However, the graduate nurses were more positive compared to the non-graduate. Findings of negative attitudes towards PWLD by professionals were also reported by Tervo, Palmer and Redinius (2004) and Au and Man (2006). In all the three studies, a background linked to direct contact with PWLD influenced attitudes. Those with higher contact showed more positive attitudes compared to those who had little or no contact with PWLD. This was reiterated by Ritchie (1999) who added that the lack of awareness of PWLD issues is another important factor. The author stated that those with little exposure to constructive debates on the values of disability, inclusion and equity are likely to show more negative attitudes towards PWLD.

Another study seeking to investigate teachers' attitudes towards the inclusion of children with special needs in mainstream schools, showed that teachers did not accept their complete inclusion. Well-intentioned genuine concerns such as those related to the nature and severity of the disabling condition of the child and availability of support resources, are used to justify partial or complete exclusionary practices (Aviramidis and Norwich 2002). A study by Ward (2007:24) also shows how parents with learning disabilities have their children taken away from them by professionals based on perceptions that PWLD are incompetent, lack ability to understand their children and will never be good parents anyway. This, according to Ward (2007) and Bigby et al (2009), can lead to a mismatch between PWLD policies and some professional actions driven by hidden underlying attitudes. However, professional attitudes towards PWLD are significantly more positive compared to members of the general population (Yazbeck, McVile and Parmenter 2004).

Drawing from Galvin's (2003) article on the marginalisation of the disabled, it would appear that negative societal attitudes are central in the processes of marginalising PWLD. The author argues that these negative images and concepts (e.g. worthless, passive, problematic, unintelligent, incompetent, disabled), which stereotype and stigmatise them become the nuclei around which their positive qualities are neutralised and their identities undermined. Society's decisions and behaviours towards PWLD reflect this undermined identity and thus pushing them to the margins of society. It is here that layers of marginalisation operate to maintain the social disadvantages they experience (Massie 2006; Vasa 2005). Scior and Scior (2011) believed that this is an essential issue which has received little attention from both researchers and policy makers. In a recent systematic review, the author concluded that high quality research in this area is limited and little is being done to tackle the lack of awareness, misconception and negative attitudes in the general population. And yet this can be the key to the success of policies aiming at promoting social inclusion, choice, independence and rights of PWLD (Scior and Scior 2011; Varughese and Luty 2010).

SOCIAL MARGINALISATION:

Social marginalisation, also referred to as social exclusion (Burton and Kagan 2003), is a contested term and a review of literature has shown that it has numerous meanings (Fisher 2011; Mathieson et al 2008). Among these meanings, social marginalisation can be defined in terms of Social Relationships (Bhalla and Lapeyre 1997), Community Participation (Room 1995) and in terms of Human Rights (Mathieson et al 2008).

Social Relationships:

Social marginalisation can occur when individuals or social groups have little or no active interactions and subsequently not able to develop meaningful relationships with people in the communities they reside. This may be through lack of social networks (Bhalla and Lapeyre 1997).

Several studies have investigated the levels of social relationships between PWLD and the communities in which they live. While findings can differ, overall they indicate that many years

after the deinstitutionalisation period, PWLD have maintained lower levels of social networks with ordinary members of their local communities. Community presence has not translated into increased interactions with the wider society as would have been hoped. The sorts of social relationships that PWLD have are largely with staff, family, volunteers and other PWLD (Lemay 2009; Forrester-Jones 2006). Evidence includes a study by Bigby (2008) which investigated changes in the nature of the informal relationships of residents 5 years after leaving an institution. Some of the findings revealed that residents did not form new relationships after relocation and regular contact with a family member even decreased. A significant number comprising 62% of residents examined did not know any other person outside the service system who knew them well or monitored their well-being.

Another study by Robertson et al (2001) which collected data on social networks of PWLD living in different community accommodation showed similar findings of lower levels of social networks. The study showed that on average, most PWLD were rarely involved in social networks that involved more than 2 people. It also showed that 83% of participants were reported to have a staff member in their network; 72% had a family member; 54%, another person with learning disability and 30% had a person outside these three categories in their network. This clearly indicates that staff, family and other PWLD were the main people PWLD had contact with in their everyday lives.

As further evidence, a recent follow-up study investigated social networks of PWLD and the types of social support they received. In this study, Forrester-Jones et al (2006) observed that the average network size was 22 members. 43% of all participants' social network members were staff, 25% were other PWLD and only a third of the members were outside the LD services. Staff members were the main providers of both emotional and practical support followed by co-peers with learning disabilities. Different from other empirical research is that the social networks in this study were considerably larger. However, the essence of the conclusion is the same as in previous studies which is that PWLD have limited social networks.

These findings provide limited evidence of PWLD developing the hoped for social relationships in their local communities. This confirms Walmsley's (2005) assertion that institutional culture is being extended to or replicated in community services. According to the European Coalition for Community Living (2010), the major focus has been on the changes on the physical environment compared to addressing how the institutional culture can be changed. Hence, by

getting stuck in the institutional culture, both staff and PWLD have not been able to take advantage of the opportunities found in community settings such as engaging in activities with local people (Lemay 2009; Leroy, Walsh and Rooney 2004). Another possible reason may simply be that local people were unwelcoming and not willing to engage with PWLD (Cummins and Lau 2003).

Community Participation:

Community can be defined as a geographical place which, in disability research, it is presented as the opposite of segregation and isolation and one that promotes a sense of belonging among the disadvantaged group (Bray, Gates and Beasley 2003: 1-2). It is mainly about what PWLD engage in or are being supported to do in mainstream activities including work, education, leisure and sports with ordinary members of the public and in ordinary places (Cole and Williams 2007).

Achieving community participation can be particularly difficult for PWLD and research evidence has shown that PWLD have continued to experience little social integration despite the many years after deinstitutionalisation. A comprehensive review of literature in New Zealand by Bray, Gates and Beasley (2003) concluded that community participation among PWLD remains problematic. The review, which included international studies, confirmed that community presence did not guarantee community participation as substantial amount of evidence showed that some community-based residential settings had no interaction with other people outside where they resided. Even where there was interaction it was only minimal, infrequent, involved small groups of PWLD and did not take advantage of the potential for further interactions. The few social activities attended by PWLD were related to specialist services which were arranged by staff and family, and the involvement of PWLD was not clearly explained. Furthermore, the study showed that staff had little knowledge about encouraging self-determination and supporting PWLD to make their own choices so that participation in social activities was not reliant on the activity programmes. The authors suggested that lack of such support from mainly staff and family was one of the most important barriers hindering community participation among PWLD. They argued that PWLD already had impoverished life experiences and lacked in many social skills that the relevant support from staff and family would have made a huge difference in their social integration.

The review noted that there is little research evidence based on the views of PWLD and also there were few studies about how to achieve the successful integration of PWLD. Some identified methodological issues related to community participation of PWLD included: use of different terminologies of learning disabilities and community participation; wide variations in sample characteristics; predominant involvement of PWLD who can verbally communicate and lack of comparison groups. But despite the variations in methodology common themes and findings emerged from the reviewed literature (Bray, Gates and Beasley 2003; Myers et al 1998).

Another systematic review of literature by Verdonschot et al (2009) studied the extent of community participation of PWLD. The results of the review indicated that community participation of PWLD occurs but the levels of participation remain generally lower compared to other disabled groups and non-disabled people. This was evidenced by the less involvement in community groups and leisure activities. Social networks are very small and friendships and social relationships are usually with co-service users and members of staff. Although some PWLD were employed they were up to four times less likely to be employed. If in a job, they would be employed in less skilled and/or low paid jobs as well as lacking that sense of belonging at work places. It was also observed that community participation is higher in community settings compared to in-patient or secure settings. The review revealed that most of the studies targeted mainly people with mild learning disabilities and the community participation of the moderate to severe learning disabled people remains unevaluated. Participation in domestic life was another area which has received little attention with only one study which briefly described this domain of community participation. As a limitation, all the 23 studies reviewed did not adequately define community participation suggesting a lack of a clear 'community participation' construct.

Further evidence of lower community participation includes a study by Minnes et al (2002) which measured community integration of PWLD. The findings showed that the majority of the participants were rated as marginalised in many day activities including in areas such as education (70%), employment (57%) and volunteer activity (53%). Baker's (2000) study compared community activity and leisure of PWLD and a control group of none learning disabled people. The results showed that participants with learning disabilities were less frequently involved in community activities and where they were, it was with carers or with friends. Their capacity of functioning more independently seemed to have an overriding role over the use of community facilities and leisure.

A study conducted outside the UK, a mixed method study, by Dusseljee et al (2010), indicated higher community participation of those with mild to moderate learning disabilities in the Netherlands. In the study, age was another factor considered. The study concluded that participation was higher in PWLD under 50years old suggesting higher risk of social exclusion for the older population with PWLD.

From the literature reviewed, social relationships between PWLD and non PWLD remain poor and community participation at lower levels than hoped. There is a general consensus among authors that at the heart of the marginalisation of PWLD is the deeply ingrained negative attitudes in the general population towards this vulnerable group. There is very little in terms of policy to change public perceptions (Turning Point 2004)

Human Rights:

Social marginalisation can be expressed in terms of lack of access to human rights which subsequently undermines the ability of the individual to fulfil their citizenship obligations (Mathieson et al 2008, Lister 1990). According to the Ministry of Justice (2006:02), human rights can be defined as:

“...the rights and freedoms that belong to all individuals regardless of their nationality and citizenship. They are fundamentally important in maintaining a fair and civilised society”

The Human Rights Act (1998) covers a range of entitlements including a right to life, protection against discrimination, right to healthcare, social right to protection of the family, economic right to work and social right to education (United Nations 2012). They are universal rights which can be accessed independent of the person's social position or status, hence, not only for a specific privileged social group. They are not only a moral or political concept but legally guaranteed by law. PWLD, like the general population are entitled to them by virtue of their humanity alone (Icelandic Human Rights Centre 2014). In addition to the Human Rights Act (1998), additional human rights instruments were introduced to protect vulnerable groups such as PWLD who have been historically discriminated. The convention on the rights of a person with disabilities provides the further protection and promotion of the rights and dignity of PWLD (United Nations 2012).

However, despite these guarantees and additional safeguards, it would seem that there is evidence suggesting that the human rights of PWLD are being violated. Griffith et al (2003) conducted a survey of human rights awareness with individuals with learning disabilities and their care providers in an Association for Community Living. The settings included group homes, semi-independent living, family homes, and specialized group homes. The results showed that human rights restrictions remain problematic across settings. While there was commitment to providing high standard of services, human rights issues were overlooked or ignored. Human rights restrictions were found in four categories: (i) access and autonomy, (ii) relationships and community supports, (iii) safety, security and privacy and (iv) control and decision-making. The restrictions differed across settings and between organisations with lesser restrictions in semi-independent living arrangements compared to all group homes and family home.

In a keynote speech at 'Time to Act for the human rights of PWLD', Values Into Action annual conference attended by PWLD, Klug (2005) explained the benefits of the human rights Act [HRA] (1998) to PWLD and how these rights were being violated. The speech gave an example of a woman with learning disability who was being denied new medicine for cancer because it was too expensive. But government eventually gave in when the woman concerned indicated that she was going to take the government to court under article 2 of HRA (1998). Article 2 (the right to life) stipulates that the government should protect all citizens from threats to their lives, and should be able to provide the necessary medicines and healthcare to allow them to live. Once she got the treatment other PWLD were able to receive the same treatment. Klug also highlighted the on-going ill-treatment of PWLD which takes place in schools, in their homes and day centres. Under article 3 (freedom from torture or inhuman or degrading treatment) of HRA (1998), the government has the duty to prevent this from happening.

In their report 'A Life Like Any Other? Human Rights of Adults with Learning Disabilities' the Joint Committee on Human Rights (2008) highlighted the extent of human rights violation problem among PWLD. The committee was clear that while human rights is a key principle of the current policy, there is a gap between the aims of 'Valuing People' and the experience of adults with learning disabilities. Although it acknowledges that there have been some improvements in the past 36 years, it observed that levels of violation of the human rights of PWLD remain unacceptable high. Among other violations, PWLD continue to face unprecedented discrimination, the unjust removal of their children from their care, little progress

in the area of voting and that they remain largely a marginalised social group. The problem was further compounded by lack of available resources to provide appropriate support to ensure their human rights needs were met. The committee concluded that respecting the human rights of PWLD should be seen as a major part of the solution of the social, political and economic disadvantages as well as the abuses they experience. For that reason the committee recommended a reinforcement of a human rights approach.

ECONOMIC MARGINALISATION:

Atkinson (1998) defined economic marginalisation (exclusion) as the lack of participation of some individuals in the labour markets. For the International Council of Human Rights Policy (2001:03) economic exclusion is the:

“... relative differences in income and standard of living of victimised groups in a given society compared with the average income of people living in that society”

According to Emerson et al (2012) and Office for Disability (2010) PWLD are among the most economically excluded groups in the United Kingdom. The Government's white paper Valuing People: A Strategy for Learning Disability for the 21st Century acknowledged that employment rates among PWLD are unacceptably lower compared to rates of all disabled people and the general population (Department of Health 2001; Office for Disability 2010). Hence, one of its key objectives is to tackle the issue of employment among PWLD, a commitment reiterated in “Valuing Employment Now” where they set out to radically increase the employment rates of PWLD by 2025 (Department of Health 2009).

A number of studies have estimated that the employment rate for PWLD is somewhere between 6 and 10% (Emerson et al 2012, Office for Disability Issues, DH 200). These percentages are considerably lower than the employment rates of all disabled people (47%) and the working age population in England at 77.3% (Office for Disability Issues 2010). A literature review by Emerson (2007) confirms the existence of high rates of unemployment among PWLD in UK (as well as other richer countries) and the significant risk of living in poverty compared to the non-disabled peers. Other evidence of low unemployment rates were identified in a study carried out by Chris Milner (2005) on the employment issues of young PWLD in Tynedale, in which of the 46 PWLD interviewed only 2 were in paid employment and the rest were doing voluntary work.

Studies show that many PWLD want to work (Department of Health 2009; McConkey 2007). They understand the benefits of work which include promoting social integration, task variety (Cramm et al 2009); greater satisfaction with life (Cimera and Burges 2011) gaining self-esteem and improving their standard of living (Department of Health 2009; Emerson 2007). In addition, they have already demonstrated that they are capable of contributing to the labour market through voluntary work and the performance of unpaid labour during their stay in the long-stay hospitals (Abbas 2012; Walmsley 2005). The question to ask is: Why then are PWLD so significantly excluded from the employment market?

Various reasons have been given as the barriers contributing to the economic marginalisation of PWLD. Some of the reasons include: restrictions brought by their physical and cognitive impairments (Emerson 2007), limited personal experience, few suitable jobs, serious commitment required from employers and the risk of losing benefits (Milner 2005); concern over costs, fear of legal liability and lack of awareness of disability (Kaye, Jans and Jones 2011). Others strongly believe that the limitations in employment are linked to lack of opportunities in education. Reinforcing this point, Barnes and Sheldon (2007) posit that the education received by PWLD in Special Needs Schools is inferior to that received by the non-learning disabilities population and is central to their underclass status in society. They are not likely to proceed to higher education and not to have received any work-related training to competitively access the labour market (Crawford 2011). An Irish study by Watson (2009) concluded that the schools did not have the relevant resources to enable systematic acceptable standards of teaching PWLD and teachers lacked support to design effective teaching programmes and the confidence in teaching such pupils. In her article 'Being included in the continuum', Northway (2006), calls for a change in focus that moves away from separateness to one that emphasises on providing the right support within mainstream classes.

But a substantial number of authors consider the negative attitudes attached to PWLD as the fundamental barrier to their employment. Barnes (1992) suggested that the traditional explanation of disability based on the medical model has continued to influence society's perceptions towards PWLD. The author argues that the medical approach assumes that the PWLD are not capable of adequately sustaining themselves and any of their dependants as a result of their impairments. Thus, their impairments are associated with being weak and restricting their social and practical skills which are required in industry (Atherton 2005). Seen as the least capable in society, they are likely to be the employers' last choice in favour of other

non-learning disabilities population. A study by Minskoff (1987) which examined attitudes about employing workers with learning disabilities found out that employers were willing to hire the physically disabled and were less positive about hiring PWLD. The study concluded that these negative attitudes were not related to lack of knowledge about learning disabilities, but either related to the prejudice against workers with learning disabilities or to lack of experience in supervising such workers.

Emerson (2007) points out that such economic exclusion can have some serious consequences on the lives of PWLD. The few studies available have consistently shown a strong association between having a learning disability, unemployment and the risk of living in poverty compared to the non-disabled peers. Where PWLD are in employment, many will be isolated from workmates, work in poorly paid jobs that are likely to be of low status, low skills, non-challenging and unrewarding (Monk 2010; Walmsley 2005; Wistow and Schneider 2003). At times they are forced to work in unsafe conditions (Monk 2010; Walmsley 2005) and may work in segregated learning disabilities only workshops (Barnes 1992). A study in Australia by Monk (2010) looked at the work carried out by PWLD at Kew Cottages from 1887 to 1995 and highlighted the unfair exploitation of patient labourers with LD working under unsafe conditions. These service users were very lowly paid or not paid at all and yet their work contributed significantly to the economy of the cottages and saved the government department they worked in wages and maintenance costs. The study also concluded that most PWLD preferred to do the unpaid work as this provided them with the opportunity to spend time constructively and because those who worked were treated more favourably compared to those who did not. Working or not, PWLD continue to rely heavily on the welfare system benefits money, which Barnes (1992) believe may help maintain their economic exclusion.

To address this problem the Government, in its new strategy for employment 'Valuing People Now: real jobs for PWLD', reiterated that employment was one of the priority areas for PWLD (Department of Health 2009). Melling, Beyer and Kilsby (2011), in evaluating progress related to employment of PWLD from 1997, concluded that significant progress has been achieved in the development of policy related to supported employment for PWLD. The authors believe the policy is clear and has been given more priority than before. Although there are no major changes in the numbers of PWLD in employment, the initiatives on the ground are helping to understand the practicalities of achieving this (Melling, Beyer and Kilsby 2011). As evidence supporting the success of supported employment of PWLD in mainstream labour market,

Weston's (2002) review of literature from Australia, USA and UK found that supported employment is successful in assisting people with complex needs into mainstream employment. However, aspects of the employment policy, the benefits system, a lack of funding, and geographical variation in provision act as barriers to success.

Underclass:

While underclass is a controversial term, it is seen by others as the term able to highlight the essential aspects of the life situation and experiences of PWLD (Bryan 2007). According to Haitsma (1989), underclass involves long-term unemployment and social situations such as lack of education that diminish abilities to connect to the labour market or income generating activities. Field (1989) believes that the following four conditions create the underclass: unemployment, widening class differences, exclusion from rising standards of living and negative attitudes of society towards the affected social group. As a result the underclass is distinct from the rest of society in terms of income, life chances and aspirations. Also, relevant to PWLD is the view by Garland (1995) who focused on society's hardening attitudes towards the disabled. The author suggested that individuals or social groups can become part of the society's underclass once considered abnormal, unwell, requiring special care and seen as a drain on society.

Bryan (2007) seemed to suggest that as a result of the sheer number and combination of these exclusionary factors (societal negative attitudes, poor social relationships, lack of community integration, unemployment and violation of rights) PWLD can be seen as one of the most disadvantaged social group in society. The fact that they are perceived as such, the author believes the term underclass can best describe this social status. Whittaker (2013) believes they may even be located below the underclass. The author described the underclass as made up of unemployed non-learning disabled population and suggested that at the bottom of this underclass are PWLD who have a life-long dependence on the state benefits.

While the Joint Committee on Human Rights (2008) does not apply this term underclass to all PWLD, they acknowledged that a few PWLD can be classified as such. In their report evidence they stated:

“There is a development of an ‘underclass’ of people with learning disabilities who do not meet the local authority eligibility criteria for receipt of services. This is a very vulnerable group. It is

acceptable that early intervention approaches can avoid later crisis- the tightening of eligibility criteria goes against this principle” (Joint Committee on Human Rights 2008:232).

CONCLUSION AND RELEVANCE TO CURRENT STUDY:

The review paints a picture of a social group which is highly marginalised socially and economically. PWLD are not visible in mainstream social activities, mainstream education and mainstream employment and their standard of living remains poorer compared to the general population. A key factor to their marginalisation is the fact that societal attitudes towards them have remained largely negative. This is the case and yet, studies with a primary focus on marginalisation are scarce and hardly any which attempt to address the issue of societal attitudes towards PWLD. In addition to contributing to the literature on this topic, this current study will take this challenge in trying to better understand these complex social difficulties they face in terms of oppression.

CHAPTER 4: VICTIMISATION EXPERIENCES AFFECTING PEOPLE WITH LEARNING DISABILITIES

INTRODUCTION:

The aim of this review is to critically consider the key research literature on victimisation experiences affecting PWLD. The goal is to synthesise the current state of knowledge related to the social difficulties PWLD experience in order to identify the gaps pertaining to current knowledge. This appraisal is important because, while a great deal of work has been carried out on the extent to which PWLD are victimised in their everyday lives (Horner-Johnson and Drum 2006), rarely has this experience been explored in terms of oppression.

THE LITERATURE REVIEW PROCESS:

The literature search was carried out between January 2012 and March 2015. The most relevant databases covered literature within sociology and nursing and included: databases PsycINFO, Medline, ESBOC and CINAHL. Internet searches for online literature and relevant websites were carried out using Google and Google Scholarly search engines. Other sources of relevant information included non-electronic sources such as book catalogues, and article reference lists. Grey literature including commissioned reports, unpublished material and organisational project papers and guidelines were considered. Table 4 presents an overview of the key search terms used relevant to the subject area of interest. These terms included the main concepts Learning disabilities and victimisation. For the key word learning disabilities, intellectual disabilities and mental retardation were used as synonyms. For victimisation, the following synonyms and/ or variations were used: abuse, exploitation, hate crime, bullying and harassment for victimisation. All the key words within the database search were located in abstracts only.

TABLE 4: Victimisation Literature Review Search Terms

Concepts	Variation/Synonym	Location
Learning disabilities	Intellectual disabilities Mental retardation	Abstract only
Victimisation	Abuse exploitation hate crime bullying harassment	Abstract only

Inclusion and Exclusion Criteria:

Table 5 highlights the inclusion and exclusion criteria used in this literature review. While there is evidence that people with disabilities in general are subjected to experiences of victimisation in their daily lives, the emphasis of this research is on PWLD. Studies which investigate experiences of children and/ or adults with learning disabilities have been included to reflect on how their experiences in adulthood are closely associated with their experiences in childhood (Heslop and Abbott (2009). The studies included in this search are from 1990 onwards. This is to reflect the limited primary research studies in this area (Horne-Johnson and Drum 2006) and lessons society has learnt from the past treatment of PWLD (Northway and Jenkins 2012). Hence, studies outside UK should help capture primary studies done elsewhere from which new ideas can be developed. Considering that with some forms of victimisation such as mate crime, have not been explicitly identified in scholarly research, evidence from literature reviews and case series or case studies will be included.

Table 5: Victimisation Literature Review Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Time Frame	1990 onwards	Before 1990
Language	English only	Non-English
Population	Involving children and/ or adults with LD	Focus on other disabilities only
Geography	UK, Europe, Americas, Africa and Asia	
Types of study	Primary research studies, secondary research studies, Literature and systematic reviews, case series/studies and commissioned reports.	Editorial articles Anecdotal stories Commentaries

Search Process and Outputs:

In total 745 articles were identified, of which 451 were duplicates resulting in 294 to be considered in line with the inclusion and exclusion criteria. Of these 219 records were excluded as not relevant to the topic of interest and/ or to learning disabilities. The full text for 75 articles were reviewed and on further screening 13 were excluded as commentaries. This resulted in 62 relevant studies which satisfied the reviews inclusion criteria. A further 5 studies which met the review inclusion criteria were obtained from additional sources such as hard copy and grey literature searches. A total 67 of relevant articles were retained that cover the different forms of victimisation experiences affecting PWLD.

Assessment of the quality of literature on victimisation:

CASP checklist was used to assess the quality of the identified studies mainly because it can be applied to quantitative and qualitative research methodologies. Each paper was analysed against this checklist and rated as good when it fully met criterion, satisfactory when it partially met

criterion and poor when it did not sufficiently meet criterion. It was noted that most studies were quantitative. Some of these studies were rated as good (meeting the criteria). For instance, a study by Brown and Turk (1994) had the strength of being one of the very few comparison studies available. By comparing variables, this was important in identifying systematic differences in sexual abuse and establishing the extent of these differences between PWLD and the rest of society. Such studies are key in clarifying assumptions and to confirm or reject findings from non-comparison studies (Reza 2011). Another comprehensive study by Mencap (1999) was rated good for mainly using a larger sample and its triangulation of methods of data collection: 904 survey questionnaires and six focus groups. This triangulation increased the validation of the study (Patton 2001). The study on bullying of children with learning disabilities (Enable Scotland 2007) was rated as satisfactory. Of its 500 questionnaires sent to self-advocacy groups and schools, it is not specified how many were completed. Others were rated as poor as was the case with study by Petersilia (1998) for the lack of robustness in describing in detail the sample characteristics, sample sizes and methods of data collection. This made it difficult to assess the validity of the study.

On the whole, questionnaires were the main method of data collection in qualitative studies. This raised validity issues due to problems of poor responses from PWLD the majority who have communication difficulties and low literacy levels and use of proxies who may not accurately reflect the views PWLD (Finlay and Lyons 2001). Hence, these questionnaires can miss significant data which other methods can generate such as semi-structured interviews, used in this current study, through probes and clarifications (Murphy and Cameron 2008).

A smaller number of the studies were qualitative. Compared to quantitative studies, the qualitative studies tended to involve PWLD as participants and/or steering group that informed the research. Semi-structured interviews and focus groups were the main data collection methods used. This is important in understanding victimisation issues from PWLD's perspectives using methods that allow deeper insights into issues affecting PWLD and in ensuring that their voices are heard. This was the case in the study 'Looking into abuse' by Northway et al (2013) and the study by the Equality and Human Rights Commission (2009) which focused on the experiences of targeted violence among disabled people including PWLD. Some articles were rated poor, particularly case studies and case reviews that focused on one person (Loveridge et al 2003 'Abused and abandoned' and Flynn (2007) 'The murder of Steven Hoskin; A serious case review'). While these provided deep insights into victimisation experiences, their findings cannot

be generalised to the wider population with learning disabilities. The sample of one is too small to be sure that findings can be applied elsewhere and can be representative of the experiences of PWLD.

While the mixed method studies were very few, the quality of their studies were highly rated. For example, the study by Beadle- Brown et al (2013) that provided both qualitative and quantitative data was rated good quality. Among its strengths was the validation of data through cross verification from its triangulation of sources of data, use of both qualitative and quantitative data and use of multiple analysts which can help in gaining consensus and multiple perspectives/ways of seeing the data (Patton 2001).

On commissioned reports, while they are not empirical studies, they provided invaluable evidence of what is happening in the lives of PWLD. For example, the report by the Joint Committee on Human Rights (2008) contained almost 200 pieces of evidence from a wide range of relevant sources such as PWLD, families of PWLD, Charities, NGO's, Government departments and service providers. Hence, such literature was difficult to classify, although it met the inclusion criteria and provided useful evidence, it scored poorly against the checklist because it was not an empirical study.

In all the different types of studies many researchers did not state whether participants involved had a formally assessed learning disabilities diagnosis or not. Use of people with a formal diagnosis help to ensure that findings are valid or truly represent the client group under investigation. This resonates well with the problem of using unconfirmed incidents of sexual abuse as real abuse and unconfirmed events of hate crime as evidence of the actual hate crime. This may not provide an accurate reflection of the experiences of PWLD. Furthermore, certain terminologies such as bullying, harassment and hate crime have been used interchangeably making it difficult to compare studies.

Based on the themes emerging from this literature view, this chapter will be structured around five sections. Section 1 introduces the definition and rates of victimisation among PWLD; Section 2 discusses the specific and common forms of victimisation PWLD experience with a focus on bullying, hate crime and sexual abuse. Section 3 considers the challenges involved in recognising and preventing victimisation of PWLD; Section 4 explores some of the causes of victimisation and Section 5 summarises the issues and gaps arising from the literature.

DEFINITION AND RATES OF VICTIMISATION:**Definition:**

Although victimisation has been a widely used term throughout the literature, few attempts have been made to provide a formal definition. Cronje and Kietsman (2009) and Kostic (2010:65-66) broadly defined victimisation as a process or mechanism in which individuals or social groups become targets of harmful actions or omissions at the hands of other human beings. A similar view is reflected by Beadle-Brown et al (2013) who stated that victimisation is the process of being a target of any negative behaviour and treatment. In these two definitions, victimisation encompasses a range of behaviours from minor acts such as staring, laughing and name calling (Beadle-Brown et al 2013); to major forms of harmful conduct such as significant damage to property, persistent bullying and harassment, serious physical assaults and in rare cases, murder (Disability Now 2013, MENCAP 1999).

Others have provided a more restricted or lucid definition of victimisation. According to Dussich (2006:118) the term victimisation should only refer to a process in which persons, communities and institutions are damaged or injured in significant ways. This damage should be profound enough to cause “a violation of rights and/or significant disruption of their well-being”. This is a standpoint supported by Hartjen and Priyadersini (2012:7) who also argued that victimisation is a term which should indicate situations where serious acts of harm need to be exposed. But the use of such a restricted definition can be problematic as experiences of victimisation are personal and subjective: what is more serious than ordinary harm to one individual may not be serious to another. Hence, a focus on what is only defined as significant or serious may not be able to adequately address the problem of victimisation affecting PWLD (Hillyard et al 2004).

Rates of Victimisation:

Partly as a result of definitional problems, there are difficulties in measuring the extent of victimisation experienced by PWLD. Some reasons why their experiences may not be formally identified may include: 1) residing in accommodation classified as institutions such as residential homes and group homes which are excluded from British Crime Surveys, 2) their victimisation may not be perceived as victimisation by professionals, the police, families and by PWLD themselves (Williams 1995), 3) only a few cases of their victimisation are reported to the police or dealt with through the legal process and many do not access services for victims with learning disabilities (Tyiska 1998) and 4) some PWLD in particular those with mild learning disabilities

might not be identified as such that a record of their victimisation will not show their learning disability diagnosis (Simley 2005).

However, some studies have tried to estimate the victimisation experiences of PWLD. The evidence in the studies reviewed show that PWLD are highly vulnerable to victimisation compared to the non-LD population. For example, Wilson and Brewer (1992) completed a study in Australia in which they compared rates of victimisation of 174 adults with intellectual disabilities with those without disabilities living in the same community. The authors found out that rates of victimisation were generally higher in PWLD compared to the rates in the general population. PWLD were 2.9 more likely to be victims of criminal assaults, 10.7 more likely to be sexually assaulted and 12.8 more likely to be victims of robbery. Their risk of victimisation was lower in auto theft as very few PWLD own a vehicle. While this study has advantages, the research is limited by subject selection bias in that participants were obtained from community learning disabilities settings (eg residential homes) which may not be representative of PWLD outside such settings or services.

Similarly, Petersilia (1998), in her written presentation to the California State Senate Public Safety Committee highlighted that people with developmental disabilities were 5 times more likely to be victims of crime. Using the national survey statistics for the state of California, the author estimated that approximately more than 5 million crimes including assaults, sexual abuse, robbery, theft, burglary and hate crime are committed against people with developmental disabilities each year compared to the 8 000 hate crimes in the general population, 1 million crimes against the elderly and 1 million cases of domestic violence related crimes each year. While the statistics are useful, there is lack of robust details in describing methodology used to get this data.

These estimates confirm findings by Sobsey, Lucardie and Mansell (1995). In their literature review, the authors concluded that from the various estimates of victimisation by different researchers, the best conservative estimate was that PWLD were between 4 to 10 times more likely to be victims of crime than the non-learning disabled population. These higher rates have also been reiterated in a report prepared for the California Senate Public Safety Committee hearings on the experiences of PWLD in the criminal justice system in 1998. In the report Petersilia (1998) points out that the higher rates are more pronounced for crimes of sexual assaults which were 10.7 times higher and crimes of robbery which were 12.7 times higher

compared to non-disabled population. Furthermore, the author pointed out that PWLD are also at a higher risk of repeat victimisation due to being perceived as easy targets by their perpetrators who can victimise with little chance of being detected or prosecuted.

According to Sorenson (2002, 2001), these high rates is evidence that victimisation in this population group are equally seriously disturbing as victimisation of the elderly, children and women. In spite of this, there is little research funding (Bouras 2004) and few researchers have shown interest in this area of study (Sorensen 2002; Petersilia 1998; Williams 1993).

SPECIFIC AND COMMON FORMS OF VICTIMISATION:

From a review of the literature, three main forms of victimisation experienced by PWLD were identified: 1) Bullying; 2) Hate crime; and 3) Sexual abuse.

Bullying:

Ireland and Clarkson (2007:14) defined bullying as an all-encompassing term which describes a range of direct and indirect forms of aggressive behaviours that occur between the victim and the victimiser. The Department of Children, Schools and Family (DCSF) (2008:01) expands this further adding that it is a behaviour repeated over time to intentionally hurt another individual or group of people physically or emotionally. Ferrington (1993) cited by Sasse and Gough (2005:13) identify as a key criteria that it must be repeated, based on imbalance of power, intended to cause fear or harm and must be unprovoked. This will include name calling, spitting, damage to property, physical harm, intimidating, humiliating, ignoring (Mencap 2000), rumour spreading and engineering isolation (DCSF 2008:01).

The National Children's Bureau (2007) assets that bullying is a huge problem across all forms of disability and yet it has received little research attention. Most literature about bullying has been undertaken mainly with children and in schools (DCSF 2008; Sasse and Gough 2005). But with the closure of large institutions and increased presence of PWLD, studying of bullying of this vulnerable group becomes relevant. A comprehensive study carried out by Mencap suggests that bullying of PWLD is widespread and is institutionalised throughout society. Findings showed that nearly nine out of ten PWLD interviewed had been bullied in the past year, two thirds are bullied regularly with a third reporting being bullied on a daily or weekly basis. PWLD cited the following as the common forms of bullying: name calling or verbal abuse, spitting, threatening statements, physical assaults (poking, pulling hair, kicking, biting, punching), stealing and being

told to leave the building. They identified the following as the common locations of bullying: public places (73%), on the bus (25%), day centre (30%), home (26%), service and leisure centres (12%) and a significant number in the neighbourhood. 75% reported to someone about their bullying, this included reporting to staff (54%), family (26%) and police (17%). However, in all cases 53% of the bullying continues after reporting.

However, the Institute of Community Integration (2000) treats these findings with caution stating that the estimate figures in the Mencap (1999) study may be too high. They believe such high estimates may lead to false belief that victimisation is an inevitable consequence for PWLD. More of such large scale research projects will need to be replicated in order to confirm or reject these high estimates.

Hate crime:

It was only in 2003 that hate crime became recognisable in law (Warner 2010). The Crown Prosecution Service (CPS) (2010) defines hate crime as any hate incident, which constitutes a criminal offence, perceived by the victim or any other person, as being motivated by hate or prejudice. In its cross-government action plan to tackle hate crime (2008 – 2011), The Home Office (2009) gives more detail. It perceives hate crime as the targeting of individuals, groups or communities for ‘whom they are’ which include their race, religion and beliefs, disabilities and sexual orientation. For PWLD, the main prejudice against them, reported in the literature, is their disability. Disability hate crime can then be defined as any criminal offence, perceived by the victim or any other person, as being motivated by hostility or prejudice based on a person’s disability or perceived disability (CPS 2010).

Many studies about disability hate crime involve people with a wide range of disabilities and only a few will identify or involve participants with learning disabilities. However, due to the limited literature on victimisation of PWLD, the few that involve PWLD have proved to be useful sources of information (Horne-Johnson and Drum 2006). Examples include a survey in Scotland by The Disability Rights Commission (2004). This was based on 158 completed questionnaires of which some were completed by 19 participants with learning disabilities. The study suggested that disability hate crime was a major issue among the participants as nearly half of them reported having experienced hate crime because of their disability. It also concluded that hate crime victimisation varied with type of disability identifying people with mental health problems as the most vulnerable (82%), followed by PWLD (63%).

Also of relevance and significance is a local study about hate crime by the Barnsley Hate Crime Group in Barnsley (Stephenson 2009). The survey of 145 participants with LD revealed disturbing crimes against PWLD, most of which confirm the MENCAP (1999) findings. The study showed that more than half of the participants were the victims of name calling and of being laughed at; 50% have been sworn at; more than 40% have been played tricks upon, pushed around, bossed around and totally ignored; about 35% have been physically assaulted; 28% have had things thrown at them, 28% received physical injuries from violent attacks and 18% have been spat at. The high levels of abuse have shown to have detrimental effects to the quality of life of PWLD in Barnsley. Many stated that they felt insecure outside their homes preventing them from undertaking their daily activities of living.

Lamb and Redmond (2007) used a web survey to ask more than 700 people and organisations to answer questions about hate crime against PWLD. Organisations that participated included PWLD Partnership Boards, advocacy groups and Community Safety Partnerships. 163 respondents with learning disabilities were surveyed and findings showed that more than 80% of advocacy groups and 75% of Partnership Boards said hate crime was a problem. Most Community Safety Partnerships (43.1%) did not see hate crime as a special problem. The study concluded that the far away boards and organisations are from PWLD, the less they are likely to understand the problems PWLD face. The disappointing finding was that very little was in place in terms of strategies and plans to deal with hate crime against PWLD.

A more recent study by Beadle-Brown et al (2013) shows that understanding the victimisation experiences of PWLD in terms of 'hate crime' can be problematic. In their study they found that PWLD and carers did not use that term in their responses. Instead they referred to PWLD being harassed, bullied, picked upon, targeted or discriminated. The word 'hate' was seen as too strong. They also established that there was no clear definition of what hate crime is, hence, carers of PWLD did not understand it and how it can be applied in law. As stated by CPS (2010), it is not always easy to prove that crime is motivated by hostility or prejudice based on the person's disability. Most of what is involved in the spectrum of disability hate crime (harassment, name calling, theft and vandalism) may be done for different reasons other than hate.

The various forms of hate crime can have serious consequences for PWLD. In their research report commissioned by the Equality and Human Rights Commission, Sin et al (2009) highlighted the impact of and reactions to such crimes among this social group. The research was divided into two phases. Phase 1 focused on literature review conducted in partnership with UK Centre for Evidence-based Policy and Practice. The second phase involved administering semi-structured interviews to people from a number of key organisations and agencies. A total of 30 disabled people with learning disabilities and/mental health conditions across the United Kingdom were interviewed. Their findings showed that many PWLD have changed the way they lead their lives on a day-to-day basis in order to minimise risk of further or repeat victimisation. These changes included taking longer routes to destinations to avoid certain places, giving up employment or school and not able to leave their homes at night. Sometimes people are forced to move homes, a move which is on its own stressful. Some of the participants felt unhappy at not being able to exert full control over their lives and having their lifestyle choices limited. Some reported deterioration in their mental health conditions with some respondents reported having thoughts of suicide as a result of their experiences. Others revealed how they live in on-going fear, their feelings of isolation and how difficult it is to minimise their risks considering the few resources they have. Other diverse impacts of victimisations were summarised to include: aggravation of existing conditions; Victims restructuring their lives; Action and aggression; Fear of disclosure and Impact on others (Sin et al 2009).

Sexual abuse:

Sexual Abuse can be defined as the involvement of anyone in sexual activities or relationships in which the person affected did not or could not consent or was pressured physically and/or psychologically to consent (O'Hara & Sperlinger 1997:158). The sexual activity or relationship is for the gratification of the perpetrator (McCarthy 1993) and it is also considered sexual abuse where the person is willing but this willingness is unacceptably exploited (Matthews 1994). According to the Sexual Offences Act (2003) these unwanted behaviours may include various elements such as rape, sexual assault, grooming and inciting involvement in sexual acts and abuse of position of trust particularly with children.

There is a great deal of literature on sexual abuse of PWLD and most studies have concluded that PWLD are at an increased risk of sexual abuse compared to the general population. Brown and Turk's (1994) findings showed high incidence of victimisation amongst women, which was consistent with previous studies (Allington 1992, Sobsey and Varnhagen 1989 and Hard and

Lamb 1987). For some cases abuse was of long standing duration originating from childhood. Abuse was reported in all levels of disabilities (severe, moderate and mild) and involved contact and non-contact types of sexual abuse. The common types of sexual abuse were of the contact type (touching (87%), masturbation (31%) and attempted/actual penetration (67%)) with a predominance of serious assaults. Participants were rarely abused by people they did not know. Perpetrators were overwhelmingly males of which the majority were other PWLD (42%), then family members (15%), staff/volunteers (12%) and other non-LD population such as family friends (14%). Forensic evidence of sexual abuse was recorded on a small number of cases and most evidence came from the victims' disclosures, changes in the victim behaviours, circumstantial evidence and from the background history of the perpetrators or victim. No action was taken against the perpetrators in half of the cases reported. Services were consistently not able to recognise and report cases of sexual abuse.

In another study, Brown, Stein and Turk (1995) reported the results of the second part of one of UK's largest incident surveys of sexual abuse among PWLD. The study confirmed the pattern of abuse reported in their earlier investigations as well as in other previous studies that: both males and females are at risk of sexual abuse; males are the main perpetrators and that PWLD are usually abused by people known to them rather than strangers. The main perpetrators were family members, service workers or volunteers and respected people who undertake important community roles. The remaining cases were perpetrated by other service users. The study also noted an increase in the abuse of males with learning disabilities. More striking was the fact that despite the increased awareness and sources of information available, little had changed in terms of recording and reporting sexual abuse. One positive note was that victims were receiving better help.

A more recent study was conducted by McComark et al (2005) in Ireland. In their longitudinal investigation of sexual abuse of PWLD over a period of 15 years, the authors, concluded that sexual abuse in PWLD may be higher than previously estimated. This community-based study examined 250 documented cases of allegations of abuse and 118 episodes of sexual abuse were confirmed following investigation by a multi-disciplinary team. This was an average of 17 allegations and eight confirmed cases per year over the 15 years. In most episodes the victim had a LD and in more than half of the episodes the perpetrator a LD. The victims themselves or families were the main reporters. The study found that more than half of the perpetrators were adolescents and PWLD and nearly a quarter were relatives. Sexual touching was the most

common type of abuse followed by episodes involving penetration or attempted penetration. The most common location was the family home, then the day service and public places. The victims themselves or their families were the common raisers of concerns of abuse.

This was an important study in the sense that it used a longitudinal study design which, according to Turk (1994), was not used previously. The study design provided an opportunity to examine in detail processes and patterns in disclosure, responding and assessing sexual abuse. In addition to confirming the high rates of abuse among PWLD and that other PWLD can be major perpetrators, the study also generated recommendations that might help to improve reporting sexual abuse among adults with LD. Another strength of the study was that it used confirmed episodes of sexual abuse which again has not been the case in several studies (Balogh et al 2001). According to Brown, Stein and Turk (1995) non-confirmed episodes of sexual abuse may not reflect the reality of the number of actual rate of sexual incidences.

The impact of sexual abuse can cause deep and long-lasting physical, social and psychological effects on the individual with LD (Sin et al 2009; O'Callaghan and Murphy 2003). A number of studies have identified these impacts and these ranged from aggression, soiling, running away (Bernard 1999) being overfriendly with strangers, inappropriate sexual behaviours, depression (Cruz et al 1988), emotional distress and behaviour difficulties, self-injurious behaviours (Beail and Warden 1995) to symptoms consistent with post-traumatic stress disorder (Fenwick 1994), paedophilia (McCreary and Thompson 1999), hallucinations (Sinason 1992) and multiple personality disorders (Fairley et al 1995). It is essential to understand that the impact will vary with the nature of sexual abuse and the individual. But in any case the impact will usually have some degree of detrimental effect on the person and those around them.

RECOGNITION AND PREVENTION OF VICTIMISATION

With all the evidence suggesting that PWLD are vulnerable to all kinds of victimisation in any setting they live, Marsland, Oakes and White (2007) point out that current adult protection practices are inadequate. The authors argue that adult protection policies predominantly contribute to achieving effectiveness in responding to abuses that have already occurred than addressing issues of prevention and protection from the outset of the abuse. Frequently, early risk warnings have been missed out and where they have been identified, they have not been acted upon. Williams (1993:163) perceives accurate recognition of victimisation as a pre-requisite step towards achieving redress.

In an attempt to improve prevention of abuse, Marsland, Oakes and White (2007) conducted a study with the aim of identifying those aspects of service cultures and environments that could act as early indicators of abuse. Semi-structured interviews administered to professionals and families who work directly with PWLD and document files held by practitioners were the means of data collection. Findings showed that abuse occurred in residential settings (nursing homes, residential homes, supported living units) and in their own homes where they lived with some support. Physical and psychological abuses were the common types of abuse reported. Many reported being involved in multiple abuses. Six main themes or factors to consider in attempts to recognise abuse were identified and these were: decisions, attitudes and actions of managers; behaviour and attitude of staff; behaviour and attitude of PWLD; isolation; service design, placement planning and commissioning, and the quality of the environment. And important measures suggested to help with minimising risks included: reducing isolation; ensuring effective commissioning, placement and service design; providing safe environments; ensuring management of staff competence and understanding how PWLD express their vulnerabilities.

Another comprehensive study by Murphy, O'Callaghan and Clare (2007) focused on identifying the symptoms of abuse of 18 service users with severe learning disabilities. This involved 15 cases of sexual abuse, 9 cases of physical abuse and emotional abuse in all cases. The family members and carers of these service users were interviewed to gather information about the abused person's behaviours and skills at three time points: 1) before the abuse began; 2) immediately after the abuse and 3) now (at time of the interview). After the first interview to gather background information for each case, it was established that the abuses had occurred in different locations: residential homes, respite, day centres and in the community. Few of these abuses were short lived and most of them occurred over prolonged periods of time. In all cases, the abuse was serious, of multiple types and often involved more than one perpetrator (most of whom were staff). The families and/or carers first heard of the abuse through contact with professionals, disclosure by the service user themselves and rarely, through the media.

In the second phase, families and/or carers were asked questions most of which referred to symptoms of post-traumatic stress disorder and others about symptoms of abuse they observed. These were divided into symptoms related to re-experiencing the event (e.g. flashbacks, recollections), symptoms of avoidance (e.g. avoiding people), symptoms of persistent increased arousal (e.g. irritability/anger, difficulty with falling asleep) and psychological and behavioural

problems (e.g. self-harm, physical illness). For each symptom comparisons were made about its frequency and severity before the abuse, during or soon after disclosure of the abuse and after disclosure. The same process was used to measure skills and behaviour (using the adaptive behaviour scale part 1 and 2) before, during/soon after disclosure of abuse and after the abuse. The impact of life events were considered again before, during and after disclosure of abuse. Findings showed that there were no problems or difficulties before the abuses. Then levels of distress, challenging behaviours and various other symptoms and behaviours increased in frequency and severity immediately after disclosure of abuse. These symptoms subsided with time as the service user recovered. But a few symptoms such as difficulty with concentration were difficult to spot and probably may not be appropriate measures to use with people with severe learning disabilities. The study also suggested that to examine the impact of abuse in people with severe learning disabilities for court and treatment purposes there is need to assess both symptoms and changes in skills, challenging behaviours and the effect of the family circumstances.

Sobsey (1994) provides a wide range of signs and symptoms of abuse which the author grouped into three categories namely: physical, behavioural and circumstantial signs abuse. The physical signs include unexplained injuries, pain or bruising; changes in sexual behaviour, stained, torn or missing clothes; unexplained pregnancy and over-sedation. Behavioural signs include: unusual behavioural extremes (hyperactivity/mood swings); unusual fear of a particular person, avoidance of certain settings, withdrawal, depression, sleep disturbances, low self-esteem, excessive weight loss/gain and excessive crying. The circumstantial signs involved drug and/or alcohol abuse by carers and devaluing attitudes by carers.

But Sovner (1986) highlights the difficulties involved when assessing a person with disabilities. Diagnostic overshadowing may hinder early identification of symptoms as well as the appreciation that something needs urgent attention. Changes in behaviour may be attributed to the person having a learning disability. This is closely associated with the effect of baseline exaggeration whereby the already existing 'abnormal' behaviours the person exhibits can make it difficult to identify changes earlier.

CAUSES OF VICTIMISATION:

Why do PWLD remain vulnerable to victimisation?

There are those who place the blame on the perpetrators of victimisation of PWLD. Sorenson (2001) believed that there are victimisers out there who deliberately target people with disabilities. He identified deep psychological distortions related to, among other things, anger, the desire to dominate and not able to tolerate differences as being central to such inhuman acts against people with disabilities. Such people often feel deeply insecure and inadequate, hence causing harm to the other person provides feelings of control and sense of superiority over others (Sorenson 2001).

Sorenson (2001) suggested that such psychological distortions go beyond the individual and extent into wider community. The author asserts that such hostilities or prejudice are still strong in the society and well entrenched in our cultures. Sorenson (2001) strongly believes work is required to tackle this general devaluation of people with disabilities if hate crimes against this population group are to be reduced. Similarly, Drinkwater (2009) suggests that the impact of the long history of being seen as a soft target, not able to defend themselves and not able to directly link with the police cannot be underestimated. The criticised practices of the past and negative attitudes and beliefs about PWLD have continued to prevail silently considering that recent surveys have not shown any decline in victimisation (Mencap 1999; Stephenson 2009).

However, others believe that PWLD have characteristics and/or exhibit behaviours that contribute to their own victimisation. For example, a study by Wilson, Seaman and Nettlebeck (1996) showed that poor interpersonal skills were associated with increased vulnerability to victimisation among victims with learning disabilities. According to Ryan (1998), this can be the case considering that many PWLD have problems with both expressive and receptive communication. They are likely not only to have difficulties with articulating their feelings, needs and experiences, but they are also open to suggestion and acquiescence (Peckham 2007). Consequently they may not be understood by others and increase susceptibility to risks such as grooming and mate crime (Henry and Chaplin 2006). Further characteristics identified by Keilty and Connelly (2001) include: social isolation, ignorance about the law, less able to detect or recognise abusive situations, afraid to challenge potentially abusive situations and their dependence on others to carry out activities of daily living.

But Wilson and Brewer (1992) found that other factors, such as living arrangements can contribute to the types of victimisation PWLD can experience. In their study, they noted that people with severe learning disabilities were likely to live in institutional accommodation

(residential or nursing homes). In such living arrangements rates of victimisation involving household property are lower and likely to be higher for victimisation against the person (physical abuse or neglect). The opposite was observed amongst those with moderate to mild learning disabilities. These are more likely to have less institutionalised housing arrangements and likely to lead more independent lives. As a result, victimisation rates against the person are lower and likely to be higher for property/household crimes compared with rates in people with severe learning disabilities.

CONCLUSIONS AND RELEVANCE TO CURRENT STUDY:

Literature on victimisation is predominantly non-primary research and there is a significant proportion of it consisted of case series, reports and commentaries. Of the few existing primary research studies, most are quantitative useful in their objective approach, but may miss useful data as what PWLD think, feel and understand about their oppressive experiences may not always be easy to quantify (Qazi 2011). Hence, this primary study used semi-structured interviews in an attempt to address this gap in literature.

Despite the gaps mentioned, the combination of quantitative, qualitative and mixed research studies have shown both higher rates of vulnerability to and the pervasive nature of their victimisation. These findings are relevant to the current study as they show that the victimisation of PWLD may not be just a problem of individual perpetrators who hate or target PWLD. But may indicate systematic acts of oppression of a vulnerable social group, which remain not fully accepted by society. This study, therefore, offers the opportunity to explore victimisation in a wider context of oppression in order to develop deeper insights into the difficulties they face.

PART TWO

METHODOLOGY

This study explored the oppressive experiences affecting PWLD living in the community with the aim of gaining a clearer understanding of the nature, impact and causes of their oppression as well as the strategies they employ to cope with such experiences. Part 1 defined the key concepts of learning disabilities and oppression and provided a detailed review of the previous research literature on PWLD experiences of marginalisation and victimisation. Part 2 discusses the methodology that was employed in order to carry out this research study. This will be structured around six chapters. Chapter 1 will outline the research design and process; Chapter 2 will detail the sampling design and method of choice; Chapter 3 will discuss the method of data collection employed; Chapter 4 provides a discussion of the data analysis process followed to examine the data collected; Chapter 5 highlights the ethical issues arising from the study and how they were overcome and Chapter 6 provides a critical reflective awareness of the researcher's role in the study.

CHAPTER 1: RESEARCH DESIGN

INTRODUCTION:

In order to gain a better understanding of the oppression being experienced by PWLD an interpretive phenomenological study was conducted. This chapter endeavours to explain how this selected design offered the optimum advantages and was appropriate for this study. Organised around 3 sections, the first section briefly explains the study's epistemological approach and provides the broad differences between positivist and interpretivist philosophical perspectives. The second section justifies the choice of interpretivism over positivism and the third section discusses the appropriateness of the interpretative phenomenological approach and how this linked with the interpretivism epistemology to provide a credible plan of action for the conduct of this qualitative empirical study.

EPISTEMOLOGY: INTERPRETIVISM

Epistemology can be defined as the branch of philosophy which addresses the questions: how can we have knowledge of reality? (Summer 2006) and what counts as legitimate knowledge? (Tuli 2010:99). It provides the philosophical assumptions underlying all research and sets the context in which all research decisions about research instruments, participants and research methods are based (Ponterrotto 2005). An interpretivist epistemological stance was adopted to guide this study.

Interpretivism is underpinned by the notion of subjectivity and the existence of many realities that vary across time and differing contexts (Voce 2004). An interpretivist starts from the assumption that society operates very differently from the natural world. Unlike the natural, physical and material things in the world, human beings enjoy a conscious existence: they try to make sense of their world and act in accordance with their interpretation of social phenomena (Darlaston- Jones 2007; Williamson 2006). Hence, it is assumed that deep analysis of people's narratives, behaviours and activities is the central vehicle towards which to develop a comprehensive understanding of our social world. The interpretivist researchers are seen as the best research instrument to study another human being. As a result they assume active roles in

data collection and analysis thus they cannot be detached from the research process (LeCompte and Schensul 2010). They should demonstrate commitment to a holistic view of the world from the research participants' views and be prepared to move beyond investigation of the observable or the objective (Qazi 2011). Due to the complexities in the social world, quantification of events is seen as difficult, inappropriate and not able to adequately advance our knowledge on the studied social phenomenon (Pope and Mays 2007).

This is contrary to positivism epistemology which assumes that there is a single and objective reality which exists beyond the human mind. This objective reality is governed by unchangeable natural cause-effect laws which are universal and not bound by time nor context (Cohen and Crabtree 2006; Voce 2004). Positivism is largely associated with quantitative studies. Emphasis is on objectivity and reliance on systematic observations and the subsequent numeric quantification of these observations to obtain accurate data of both natural and social phenomena (Qazi 2011). The researchers have to distance themselves from the subject of study so that the research is free of subjective biases (Tuli 2010).

WHY THIS STUDY ADOPTED AN INTERPRETIVIST EPISTEMOLOGY?

The key reasons why the interpretivist approach is more appropriate to the methodological construction of this study are three fold:

Firstly, the experiences of PWLD are the primary research object of this study. Employing the positivist epistemology that emphasises on objectivity and the existence of a single reality would not have been the most suitable for studying subjectivity and understanding the various experiential realities from the participants' perspectives. The interpretivist epistemology, which rejects the idea of studying social phenomena the same way as natural phenomena and focuses on experiences, interpretation and meanings, offered the optimum advantages that helped to effectively explore more holistically the lived oppressive experiences affecting PWLD. The approach connected well with the study research design which employed methods tailored to effectively help the participant not only to return to their historical complex and sensitive lived experiences. But also to explore these experiences with the researcher and to enable the researcher to get further deeper into the essence of these experiences.

Secondly, the few available studies have predominantly adopted a positivist approach and the objective knowledge generated has not been able to significantly advance our understanding of

the oppressive experiences affecting PWLD (Horner-Johnson and Drum 2006). While such studies have highlighted higher rates of victimisation among PWLD compared to the general population and other disabled people, they have neglected the detail of these negative life experiences. What PWLD think, feel and understand about their oppressive experiences is not always easy to quantify (Lincoln & Denzin 2003) and even so, presenting such data statistically may not achieve a more realistic feel of the human side of the oppressive world experienced by PWLD (Qazi 2011; Frank and Polkinghorne (2010). Hence, the interpretivist epistemology provided a better approach offering alternative means of not only for exploring further the areas already highlighted by the quantitative studies but also examining questions not previously explored in terms of oppression. This was an essential attempt to develop new knowledge that can help increase awareness of the profundity of the negative life experiences PWLD endure and potentially trigger changes in policies that may improve the lives of this social group.

Thirdly, it was essential that the voices of PWLD regarding their oppression be heard. Walmsley (2005) points out that historically research about PWLD predominantly reflected the views of academic researchers and a significant number of the studies were used as means of legitimising their institutionalisation. While some improvements have been noted in terms of PWLD participating in research studies, this lack of inclusive methodologies has continued to prevail (Sheffield University 2012). This is what Evans (1981) is referring to as the silent minority as does McClimens et al (2007) and other authors such as Atkinson (2004), Williams (1995) and Sorensen (2002). Interpretivism allows the voices of such hidden marginalised people in society to be heard on matters that affect their lives (Ashworth 2003; Walmsley and Johnson 2003). Its emphasis on the use of data collection methods that engender active interactions between the researcher and participants to seek for rich qualitative data was central to enabling PWLD voice their experiences of oppression.

INTERPRETIVE PHENOMENOLOGICAL ANALYSIS RESEARCH DESIGN:

Crotty (1998) defined a research design as the strategy, plan of action or process underpinning the choice of and use of specific methods of population sampling, data collection and data analysis. The Interpretive Phenomenological Analysis (IPA) methodology guided the design and conduct of this study. IPA can be defined as an experiential qualitative approach designed to explore in detail the processes through which research participants make sense of their personal and social world (Biggerstaff and Thompson 2008, Smith and Osborn 2007). Its emphasis is on meaning and sense-making with the aim to understand and interpret significant human

experiences or events as perceived by the individual in context (Ivey 2013; Reiners 2012). IPA can be understood as a research design which has its own ideas about sampling (purposive) strategies, methods of data collection (interviews) and approach to the analysis of qualitative data (IPA). Distinctive to this approach is the combination of its phenomenological, interpretive and idiographic aspects.

The Phenomenological Aspect: This aspect is concerned with the study of human experience (Smith and Osborn 2007). The experience can be in the form of events and situations but it can also be experience in terms of perceptions, thoughts, emotions and consciousness (Smith 2009). The phenomenological aspect of IPA is a process that allows research respondents to go back to the phenomenon to identify what they experienced and to provide clear and undistorted descriptions of how they experienced the phenomenon in question (Smith 2009, Hancock 1998). Hence, this aspect acknowledges the dynamism of the research process in which the researcher has an active role to play in exposing human experiences from the standpoint of the research respondents (Smith and Osborn 2007:53).

The Interpretive Aspect: This aspect of IPA emphasises on meaning and developing a sense of understanding of the participants' subjective experiences (Smith 2004). It is grounded in hermeneutics which Heidegger (1962) defined as a theory of interpretation developed on the assumption that human beings are not passive spectators of their lives. The interpretive process is seen as critical in enabling what Smith (2004) identifies as 'double hermeneutics'. The research respondents seek to self-understand through self-interpretation in order to make sense of their personal and social world (Dreyfus 1994). Then, the researcher attempts to make sense of the participants trying to make sense of their world (Smith and Osborn 2007, Brocki and Wearden 2006). This allows the researcher to move beyond factual accounts or descriptions and to delve into interpretations and meanings that are essential in gaining deeper insight into human subjective experiences (Pringle, Hendry and McLaffety 2011). As a result, the non-detachment of the researcher from respondents is not seen as a problem (Laverty 2003). Their preconceived ideas or opinions, which they believe are impossible to entirely bracket (Benner 1994), become part of their experience they use to formulate research questions, develop a research design and to interpret other peoples' experiences (Balls 2009).

The Idiographic Aspect: The idiographic aspect of IPA focuses on the individual (Smith 2004). The individual is seen as having unique aspects from which richer descriptions with more

contextual detail of their experiences can be obtained. It is an aspect that enables the researcher to get closer to the respondent, focus on detail and develop commitment to in-depth analysis (Smith and Osborn 2007). This intensive and thorough approach helps to capture the essence of experiences and to develop a global understanding of the individual, which is seen as central to the success of IPA studies (Biggerstaff and Thompson 2008).

The Inductive Aspect: IPA is inductive in the sense that the analysis is data driven and not motivated by the restrictions imposed by the employed methodology or by the researcher's theoretical interest or analytic preconceptions (Clarke 2006). Themes and research findings emerge from the data and its starting point is not a hypothesis. According to Thomas (2003) the inductive approach allows for the condensation of thick raw data into meaningful summarised formats, establishment of links between the different components of the research and the development of models or theories relevant to the research.

According to Finlay (2008:02) an IPA researcher asks the following questions: "What is this kind of experience like?", "What does the experience mean?", "How does the lived world present itself to me (or to my participant)?" In line with these questions, this IPA study involved gathering dense data related to a wide range of oppressive experiences of personal significance to PWLD living in the community. Data collection was characterised by a single long, intensive and in-depth interview to each of the 22 participants who took part in the study. Participants were selected either because they were willing to share their lived experiences of being oppressed or to share experiences of directly witnessing the oppressive encounters affecting PWLD. The analysis of these shared experiences were key to understanding the common forms of oppression and how they impact on the lives of PWLD.

WHY IPA IS SUITABLE FOR THIS STUDY:

There are four main reasons why an interpretive phenomenological design is suitable for the current study: Firstly, the literature review has highlighted the overwhelming need for qualitative primary data in order to develop a broader understanding of the negative life experiences among PWLD (Horner-Johnson and Drum 2006; Harvey 1999). This is considering that few studies have investigated life experiences of PWLD in terms of oppression (Harvey 1999). These have been predominantly quantitative research which tended to negate the subjective experiences and meanings (Qazi 2011) and on their own have not been able to adequately provide the required comprehensive understanding of oppression among PWLD (Pope and Mays 2007). This need for

quality and depth of knowledge as opposed to need for quantification was necessary to achieve a more realistic understanding of the human side of oppression of PWLD that could not be offered by numerical or statistical data (Qazi 2011). The interpretive phenomenology focus on interpretation and in particular meanings provided the optimum advantages that allowed the study to be organised around strategies that helped the researcher to: have direct contact with participants; generate dense descriptions about PWLD's life experiences and perceptions and develop deep insight into PWLD experiences of oppression. Characterised by in-depth interviews and intensive data analysis, the research design made it feasible to answer all the research questions and better understand both individual and shared lived experiences of oppression among PWLD.

Secondly, an IPA design is justifiable for this study because of its suitability in explorative research that seeks to understand significantly complex, sensitive or emotionally related life experiences and in particular those problems influenced by multiple factors (Ivey 2013). In this study, the overall aim is to gain a better understanding of the nature, impact and causes of the oppressive experiences affecting PWLD living in the community. The literature reviewed has revealed that PWLD experience multiple layers of oppression involving very intricate processes (Harvey 1999). According to Walshman (2009) an IPA research design is suitably employable to tackle such a world of complex lived experiences, which can be coloured and shaped by the individual, history, politico-economic factors and society at large. The author argues that it is a design tailor-made to closely examine accounts of people's experiences grounded in everyday life from the perspective of the participants themselves. This strength is even more relevant where other potential research designs such as ethnography and grounded theory were not possible to employ as discussed under the sub-topic employing other methods.

Thirdly, it is the degree to which the IPA approach is enshrined in the interpretivist epistemological stance that facilitated the connectedness of the various research processes involved in this empirical study. The principles of both interpretivism and interpretive phenomenology intersect in their emphasis on direct interaction with participants, studying the social phenomenon as a whole (rather than variables), investigating the phenomenon in its natural setting and in the existence of multiple realities. IPA allows the researcher to enter into a close research relationship with the research participants as advocated by the interpretivist philosophical stance (Qazi 2011), which is key to the extraction of rich data, accurate

interpretation of experiences and the in-depth understanding of meanings participants give to their social worlds (Williamson 2006).

Finally, the fact that IPA provides PWLD with opportunities to explore their oppressive treatment can be seen as an important part of their empowerment in this attempt to reduce a life-long experience. While resources and time constraints made it impossible to involve participants in the actual design of the project, the IPA design offered participants opportunities to tell their stories of experiences of oppression and reflect on these negative life experiences in a way they might not have done otherwise. It was an opportunity for them to reveal those issues they considered relevant to their needs and the detail they believed can help inform the necessary social policy changes (Balls 2009). This is consistent with Walmsley and Johnson's (2003:16) view that an inclusive research study with PWLD is empowering if it addresses issues that matter to them, accesses and represents their views and can help improve their lives. For these reasons, it is hoped that this study, when disseminated, can lead to the empowerment of PWLD. Similarly, studying life experiences of PWLD in terms of oppression is relatively recent (Harvey 1999; Northway 2004) and the topic is sensitive and complex issues that involve PWLD as research participants only was a necessary step towards understanding how similar future studies can attempt to fully involve them.

IPA matched the purpose and aims of the study. Figure 1 below provides a summary of the research design and processes for this study.

Figure 1: Research Design and Processes

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Adapted from Crotty 1998

CHAPTER 2: SAMPLING DESIGN AND METHODS

INTRODUCTION:

This chapter addresses the sampling methods and strategies used in this study. The chapter will be organised into four sections: Section 1 explains the main differences between probabilistic and non-probabilistic sampling designs and the justification for selecting non-probabilistic approach; Section 2 details the sampling method appropriate to IPA which in this case is the purposive sampling technique and how this was best suited for the study; Section 3 explains how the sample was located and accessed and provides a detailed description of the nature of the sample.

PROBABILITY AND NON-PROBABILITY SAMPLING DESIGN:

Sampling designs can be classified into probability and non-probability samples (Higginbottom 2004). In probability samples every person or unit in the population has an equal chance to be accurately selected in the sample through a form of random selection (Trochim 2006). The focus is on numerical data and is associated with quantitative research (Saumure and Given 2008).

Such sampling methods include simple random sampling, stratified random sampling, systematic random sampling, cluster random sampling and mixed random sampling which uses a combination of two more methods. In simple random sampling each person in the population has equal probability of being randomly selected to participate in the study. This could be by drawing names out of a hat or from a computerised table with a complete list of the targeted population. Stratified random sampling first categorises potential participants into identifiable subgroups or strata that do not overlap. This can be categorised according to age, gender and economic status and selection is then undertaken from each stratum (Trochim 2006). The systematic random sampling involves selecting every n^{th} element after a random start from a population list (Kitchenham and Pfleeger 2002).

On the other hand, non-probability samples are any methods where selection of the sample cannot be accurately determined and the researcher uses their judgment to select a sample based on a predetermined criteria (Saumure and Given 2008). The judgment is determined by the methodological approach or topic of study and not by the need to establish generalisation (Higginbottom 2004). The methods focus on generating data and are associated with qualitative research. Such methods include convenience sampling, purposive sampling, theoretical sampling, selective sampling and within case sampling (Higginbottom 2004:15) and snowballing (Saumure and Given 2008). In convenient sampling participants are readily available and are willing to participate in the study (Kitchenham and Pfleeger 2002), Snowballing involves asking those currently in the study to nominate others who meet the inclusion criteria and willing to take part (Saumure and Given 2008). In purposive sampling the researcher targets participants with certain characteristics or features that help to answer the research questions. Theoretical sampling enables new domains to be explored during the process of the research and within case sampling involves the selection of participants within a specific group (Higginbottom 2004).

The key distinction between probability and non-probability sampling methods is that probabilistic sampling aims to recruit an unbiased sample which is representative of the population under investigation that objectivity and generalisation of the study findings can be achieved (Higginbottom 2004; Kitchenham and Pfleeger 2002). This focus on representation, objectivity and generalisation links probability sampling with quantitative research and positivism epistemology. Non-probability sampling methods are not concerned with objectivity or generalisations of findings but concerned with complexities of the phenomenon under study and where researchers want to identify the existence of a problem (Lund Research 2012). The

methods represent the sample in a way that the researcher can describe or develop understanding of the population (Davis, Gallardo and Lachlan 2012). It is this explorative nature and the need to develop a deeper understanding of a social phenomenon that links non-probability sampling methods with qualitative and interpretivist approaches, which have been employed in this IPA study. Hence, this study employed the non-probability sampling method which in this case is the purposive sampling method.

SAMPLE SIZE:

In IPA studies sample sizes are usually small (Smith and Osborn 2008, Onwuegbuzie and Leech 2005). The sample size will not be determined by the need to ensure generalisability but to yield insight and in-depth understanding of the oppressive experiences of PWLD and the need to adequately answer the research questions (Grbich 1999; Marshal 1996; Ploeg 1999). Since data will be analysed through IPA, the sample size will also be influenced by, among other factors, the researcher's commitment to an in-depth case study type of analysis, the richness of the data collected and other circumstances which can restrict the individual researcher's work (Smith, Flower and Larkin 2009:51). However, one has to ensure that sample sizes are not too small such that it becomes difficult to reach data saturation and informational redundancy. It should also not be too big that deep analysis is difficult to achieve (Sandelowski 1995 cited by Onwuegbuzie and Leech 2005:3). Some recent studies involving IPA data analysis on experiences of PWLD have included six participants (Isherwood, Burns, Naylor, Read 2007; Mitchell, Clegg and Fumiss 2005) and others, nine participants (Brown and Beail 2009). Smith and Osborn (2007:57) recommend five or six participants specifically for students but some studies have included the range between seven and ten with some studies using samples as high as 15 participants. For this study, a small size sample of 22 participants was interviewed.

PURPOSIVE SAMPLING METHOD:

Purposive sampling is nearly always the sampling method of choice in IPA research projects (Smith and Osborn 2007). The study involved eleven participants with learning disabilities living in the community and eleven practitioners who work with PWLD in community-based settings. Both PWLD and practitioners were recruited through the purposive sampling technique. This is a non-probabilistic method which is not based on statistical formulae (Roberts 2004). Selection of the sample relies on the judgement of the researcher guided by the research questions, research design and the population being investigated (Saumure and Gavin 2008). The aim was to recruit the most appropriate participants with the richest experiences and opinions that address the

research question or topic (Marshall 1996). The selected PWLD are seen as the experts in their experiences of oppression and would be the best people to describe and explain these experiences. Practitioners who work with PWLD are among those with on-going contact with PWLD and are likely to provide valuable information about the life experiences of PWLD.

Smith and Osborne (2008) point out that there is a strong link between purposive sampling and an IPA research design. The authors suggested that IPA designs almost always involve purposive sampling techniques. The quest for achieving rich descriptions in purposive sampling is in line with the main tenets of the IPA approach which are concerned with generating thick descriptions that help better understand or explore a social phenomenon (Biggerstaff 2008). With this study focusing on life experiences of a specific vulnerable group with learning disabilities, the purposiveness of the sample selected was more appropriate in order to answer the research questions which address issues that affect their lives.

Opportunistic Sampling Technique:

Initially, the quota proportional sampling technique was the sampling technique of choice. The quota proportional sampling technique allows for the groups of people being studied to be recruited in proportional to the population they represent (Lund Research LTD 2012). The aim was to ensure that both males and females are adequately represented so that experiences of oppression could be compared and contrasted by gender. But this had to be abandoned due to the difficulties experienced in finding sites willing to host the study and particularly, difficulties in recruiting females with learning disabilities. As a result of this recruitment problem the sampling strategy ended up being opportunistic.

Opportunistic sampling strategy involves taking advantage of events as they unfold to select cases as the opportunities arise during the recruitment process itself (Patton 1990). This is not planned in advance. According to Patton (1990), this strategy is a variation of purposeful sampling method as those selected should meet the criteria of cases that can provide rich information which address the research question (Patton 1990). This can be adopted when recruitment of people is difficult as was the case in this study (Holloway and Wheeler 2013).

LOCATING AND ACCESSING THE SAMPLE:

Three organisations acted as hosts. The first host was a Learning Disability Advocacy Group in Derbyshire. The group consist of PWLD who live in the local community areas, many lived in

supported accommodation arrangements. The Group meet on a weekly basis and on other agreed dates. They discuss issues affecting PWLD, support each other and other PWLD outside the group and are involved in campaigns against maltreatment of PWLD in general. Another Learning Disabilities Advocate Group in Yorkshire acted as a second host organisation. The group meet regularly to discuss issues affecting PWLD in general and in particular, issues affecting parents with learning disabilities. Not all group members are parents or were married. The group is also involved in campaigns to highlight the plight of PWLD and parents with learning disabilities. The third host was a Housing Association which provided supported accommodation to PWLD in South Yorkshire. The association provided support which ranged from a few hours to full support in areas such as: managing budgets, personal care and shopping to providing full 24hour full care.

In this study, gaining research access to PWLD from these host organisations was a three-tier process due to the hierarchical nature of the service structures. PWLD were not directly consulted until the third stage of the accessing process.

The first stage, involved sending letters to senior figures in organisations, which according to Nind (2008) is an essential step that needs to be taken in order to secure a formal agreement to proceed with the study. Therefore, 10 key organisational Chief Executives were contacted via postal mail. Only 2 quick responses were received via email from London and Bradford within the first week of sending the letters. Another was received after a month from Cardiff and the remainder did not respond despite the follow-up attempts made. Of the three which responded, two organisations made telephone contacts with the researcher to obtain further information. One of the organisation assisted by advertising the project in its monthly bulletin and the other made arrangements to meet with the researcher. After the meeting they requested for further information including University ethics approval, which was sent. There was further telephone communication and the organisation agreed access to PWLD and to members of their staff. But at some point there was a change of interest in the research, interest which eventually faded away. Efforts to contact the organisation were fruitless and another set of fifteen organisations found on the internet were contacted this time by email. From the fifteen only three responded and again they showed some positive interest at first which faded with time. Their requests for further information and explanations were honoured and communication with them was made as appropriate. Follow-ups of the other organisations which did not respond were made to no avail.

At this stage, it was clear that there was a problem and getting past the senior manager gatekeepers was proving to be the most difficult task of the study. This was the case despite having ensured that all the information asked by the gatekeepers was readily available. This included a sound research proposal, evidence of project approval by the University ethics committee, participants' information sheets, consent forms and the reasons why those particular organisations were selected. While one needed to understand that this is your research project which people may or may not be willing to participate in, it was important for the researcher to understand the possible reasons for this difficulty with access of PWLD. According to Johl and Renganathan (2010) and Lennox et al (2005), access to PWLD can be denied despite the researcher following proper conduct and procedure. The authors argue that this can be the case where the subject matter deals with sensitive issues or vulnerable people. The senior managers are seen as an extra layer of protection of exploitation and abuse by researchers (Lee 2005). They will usually need to be convinced that the PWLD they protect will benefit from the study and that the research project is fair to the vulnerable before permission is given to conduct any study with them (Nind 2008; Lee 2005). It is possible that this could have influenced the senior managers of different organisations to deny the researcher access to PWLD in their organisations

But other reasons for denying access may not have anything to do with protecting the vulnerable adults. According to Lewis and Porter (2004), senior gatekeepers occupy a powerful position in deciding what is researched and whose voices are heard. They will have their own views of the value of the research which may be different from that of PWLD themselves. They can deny access for a wide range of reasons including fear of criticism, belief that the participants will not benefit, lack of confidence in the competence of the researcher, not enthusiastic about research (Lee 2005), getting overwhelmed by requests for research (Nind 2008) and focusing on the organisation's competing objectives (Lennox et al 2005).

Other factors could have also come into play such as being a PhD student the project may be seen purely as educational rather than for the benefit of participants, organisations may only be willing to deal with big names or organisations for various benefits and in the this study, being a non-native of this country could have contributed to the limited interest in allowing access. There is also the possibility that the recent panorama programme about the abuse of PWLD in Winterbourne, Bristol, made it harder for organisations to allow access to PWLD and those who support them. The timing of the project will make organisations to become suspicious of the

study and can lead to fear of criticism of the organisation by the researcher or in the research findings (Lee 2005).

Having experienced continued low response a different strategy was taken. This involved contacting organisations using emails instead of postal letters, advertising the project on popular learning disabilities websites/forums in order to reach to more organisations and having direct contact with people at upcoming learning disabilities led conferences. Organisations who were willing to provide access would then contact the researcher themselves. The research project was advertised on the LD Forum run by the Foundation for PWLD. About ten organisations responded to the research advertisement and of these only one organisation actually allowed access to two PWLD. A local organisation invited the researcher to meet the chief executive officer and one potential staff participant but never went beyond that. The remaining eight only went as far as promising to provide access to potential participants with PWLD and staff who support them. Then there were some very positive outcomes when the researcher attended a learning disabilities conference. Two interested organisations were met at this conference and they allowed access to nine PWLD and one member of staff.

Once a response of interest in the study was received and the senior managers granted permission to meet with other members of their organisations, the relationship between the researcher and the organisation became a key aspect of obtaining access. Each gatekeeper was different and the researcher had to find the appropriate approach to build and maintain relationships not only with the senior figures but also with other key members of that organisation. This involved showing on-going and consistent commitment, competence and professional presentation with regards to the research topic or objectives. Based on Johl and Renganathan's (2010) ideas that it may be helpful to be aware of the gatekeeper's hidden agendas or ideologies, some effort was made to modify how the study is perceived in line with organisation attitudes. This positive researcher-organisation relationship ensured that both organisations and researcher learn from each other on the subject matter of interest.

In the second stage, contact was made with practitioners working more directly with PWLD who were nominated by senior managers. This was another layer of gatekeepers the researcher had to work with to find out who, how, where and when to meet with potential participants. In all cases the researcher had to provide written information and undertake oral face-to-face discussions about the project with these practitioners. The two aspects of the process were

mainly for them to undertake further assessments of the researcher and an opportunity for any clarifications required (Lenox et al 2005). This also was part the on-going effort to establish rapport and trust with different members of the organisation before making contact with the potential participants with LD. With the permission already granted by senior managers of the concerned organisation, this stage was less difficult and led to the third stage without major delays.

In the third stage, PWLD were directly contacted and introduced to the researcher by their keyworkers who later facilitated further meetings and support as and when it was needed throughout the data collection period. At this stage, key issues of importance were: 1) establishing rapport with the potential participants; 2) explaining the purpose, benefits and potential risks of the study to participants; 3) accessing for ability to gain consent and eventually gaining informed and voluntary consent to participate in the study, which will be discussed in detail in the data collection chapter (Chapter 3).

Accessing practitioners was not as complex as the process of accessing PWLD but had its challenges. It was hoped that adequate practitioners could be recruited through the initial initiative of advertising the study on LD forums and having face-to-face meetings with them at conferences for PWLD, but this was not the case. Only as few as two practitioners who met the selection criteria were recruited through this approach which triggered changes in the recruitment strategy. Hence, the snowballing technique, which is a subset of purposive sampling, was successfully utilised to recruit more practitioners until the required numbers were reached. The only two practitioners to be identified then recommended other potential participants who met the criteria. The same process was repeated with the next person until fifteen people were snowballed. Each potential participant negotiated with their own organisations about whether they could participate in the study or not. Of the fourteen snowballed potential participants, five were not given permission to participate and did not take part.

NATURE OF THE SAMPLE:

People with Learning Disabilities:

As shown in Table 06, those who participated in this study were adults living in the community who had either a mild or moderate learning disability aged between 20 and 46 years. They spoke English (this was a requirement due the cost of translators), all identified themselves as Caucasian and 9 out of the 11 respondents were males. Some attempt had been made to get

women involved in the study, but this was less successful. One reason for this may be due to the fact that the researcher was a male (Leduc 2009). PWLD often suffer from a range of other difficulties such as mental or physical health problems (Hardy 2010). However, at the time of the study the participants reported that they were feeling well and so were able to give their informed consent to take part in the study.

Practitioners:

Those who participated in this study were practitioners who were giving direct care or support to PWLD living in the community. Table 07 shows that practitioners were mostly nurses and also included practitioners such as victim advisors and advocates. Their experiences of working with PWLD in the community varied from 3 to 25 years.

Tables: Details of Participants

Table 06: Characteristics of PWLD Participants

ID	Diagnosis	Gender	Age	Ethnicity	Living Situation/ Accommodation	Education: School Attended	Employment at time of interview	Marital status
1	Mild LD	M	46	British white	Council Accommodation	Attended SEN primary and secondary schools. Attempted further education	Employed part time and also do voluntary work	Married
2	Mild LD	M	45	British white	Supported Living	Attended SEN primary and secondary schools, no further education	Employed part time.	Divorced
3	Mild LD	M	46	British white	Council Accommodation	Attended SEN primary and secondary schools,	Employed part time. Doing voluntary work	Married
4	Moderate LD Epilepsy Down Syndrome	M	34	British white	Residential Home	Attended SEN primary and secondary schools,	Unemployed.	Single
5	Moderate LD	M	27	British white	Supported Living	Attended SEN primary and did not complete secondary schools education.	Unemployed, On welfare benefits, doing voluntary	Single

						Cannot read & write	work	
6	Mild LD	M	59	British white	Residential Home	Attended SEN primary and secondary schools	Unemployed. On welfare benefits. Doing voluntary work	Single
7	Mild LD Blind	F	29	British white	Residential Home	Attended SEN primary and secondary schools. Went to college	Unemployed. Doing voluntary work	Single
8	Mild LD	F	44	British white	Own Accommodation bought by family	Attended SEN primary and secondary schools,	Unemployed.	Single
9	Mild LD	M	59	British white	Residential Home	Attended SEN primary and secondary schools,	Unemployed.	Single
10	Mild LD Autism	M	45	British white	Supported Living	Attended mainstream school. Did 'A' level, no further education	Unemployed. Doing voluntary work	Single
11	Mild LD Epileptic	M	41	British white	Supported Living	Attended SEN primary and secondary schools, no further education	Unemployed	Single

Table 07: Characteristics of Practitioner Participants

ID	Practitioner	Gender	Years of Experience working with PWLD	Care Setting
1	Specialist Nurse	F	13	Residential Homes
2	Senior support worker	F	10	Advocacy Group
3	Service Manager	F	28	Residential Home and Supported Living Accommodation
4	Learning Disabilities Nurse	F	10	Community

5	Support worker	M	03	Community Rehabilitation Unit
6	Specialist Learning Disabilities and ADHD Nurse	M	11	Community Clinic
7	Victim Support Worker, Equal Access to Justice Co-ordinator	M	07	Charity for victims of abuse (Telephone Helpline Centre)
8	Learning Disabilities Nurse	M	10	Supported Living
9	Senior Support Worker	M	05	Residential Home
10	Deputy Manager	F	11	Residential Home
11	Senior Support Worker	M	09	Supported Living

CHAPTER 3: METHODS OF DATA COLLECTION

INTRODUCTION:

This chapter discusses the methods used to collect data for this study. It is organised in four sections. Section 1 considers a range of possible methods that could be used in order to obtain information about PWLD experiences of oppression; Section 2 presents the chosen method of data collection for this study, namely, semi-structured interviews and states the advantages of employing this approach; Section 3 discusses the interview guide and section explores the challenges encountered and how they were overcome.

CONSIDERING POSSIBLE METHODS:

This section considers different possible methods that could be used in order to obtain information about PWLD experiences of oppression. This includes the use of questionnaires. These have been tried in various studies and found to be problematic when they are used with PWLD. For example, a recent joint study by BILD, Mencap and Department of Health (2013) used a questionnaire to 75 PWLD and 191 family members/carers regarding the care and treatment provided to PWLD by the NHS. The study found out that designing the questionnaire into 'easy read' format to ensure it is understood by PWLD lead to some methodological problems. Although the easy read format maximised completion rates, it meant that questions only included fewer response options which affected the richness of the quantitative data. It also meant that the concepts which were simplified became even more ambiguous. They also found out that some questions became too generalised which made it harder for PWLD to answer them. As a result the survey was not able to capture the varying experiences it was meant to capture.

A literature review on the use of questionnaires by Finlay and Lyons (2001) found out that a combination of factors including communication problems, lower IQ, low literacy levels and limited life experiences among PWLD contribute to the difficulties in the use of questionnaires in this population. Although attempts were made to counter these problems, the authors observed that there were on-going difficulties associated with asking PWLD via questionnaires which in turn, threatens validity of the research. The problems included poor responses where questionnaires: use constructs and vocabulary PWLD are not familiar with; and ask questions which require PWLD to use higher level cognitive skills such as making judgments, estimates, comparisons and generalisations. Also they can be a problem where the questions reflect the concerns of the researcher rather than those of the respondents and this seemed to be the case with quality of life (QoL) questionnaires which have been criticised for using professionals' judged criteria of what the important indicators of QoL are. The authors believe that the validity issues associated with the use of questionnaires with PWLD is enormous such that more research is needed to find ways to improve design of questionnaires in this social group.

A Mencap (1999) study sent 5,000 questionnaires about bullying of PWLD across the United Kingdom and Northern Ireland. Murphy and Cameron (2008) suggest that such an approach presents with significant problems. One of which is the fact that of denying a voice to those who can't read/write and allowing the carer to take control of the communication by completing the questionnaire on their behalf. This can lead to validity problems as the responses may not be an accurate reflection of the person with learning disabilities (Finlay and Lyons 2001). Even where

PWLD complete the questionnaire themselves, the opportunities offered by semi-structured interviews to follow and explore issues raised by the participants and to seek clarifications, would be missed (Kvale 1996). According to Murphy and Cameron (2008), this is an important point as many PWLD have difficulty generating comments and ideas without probes, prompts or questions from others. It is this missing data the survey would have failed to capture in order to develop potentially new knowledge.

Also, the use of focus group(s) was considered. These too have been tried in various research projects with PWLD. Nind (2008:11-12) pointed out that the “mix of behaviours, communication difficulties, sensory impairment and histories of PWLD” can be a barrier in producing the required group dynamics necessary for a successful focus group. Similarly, this has been echoed in a recent review of literature on the use of focus groups with PWLD. In the review Kaehne and O’Connell (2010:134) noted that facilitating productive interactions in focus groups with PWLD may be hampered due to lack of their ability to: explore a given topic with minimal guidance, engage in a meaningful debate, reflect on other participants’ perspectives, and to deal with opposing views. The authors also highlighted the problem of time and resource constraints which make it harder for researchers to start PWLD focus groups from scratch. They found out that the majority of the focus groups used were from existing self-advocacy groups, many of which have been over-researched and likely to produce rehearsed responses and answers sanctioned as correct in previous focus group discussions. In turn, this can result in having the same or similar results being produced with little or no impact on policy or practice (Kaehne and O’Connell (2010:141-142).

On reflecting on the use of focus groups in their study, Fraser and Fraser (2001) gave examples of the challenges they faced. One of the examples referred to one focus group interview where members failed to engage with each other to produce a group discussion to a point of having individual responses similar to one-to-one interviews. This limited interaction was not in line with the aims of focus groups of enabling group contribution to challenge individual thinking and resulting in richer responses (Fraser and Fraser 2001:229). Similarly, in Moonen et al (2010:05) experiences, focus groups with PWLD can get very disruptive in particular where it involves diverse members with different clinical needs and attention. Many and specifically those with autism may not be confident to participate in groups with people they are unfamiliar with.

Considering the communication and cognitive impairments already stated, focus group approaches may not be empowering for all group members (Gibbs 1997). The less articulate, the shy, those with speech impediments and those who have difficulties related to suggestibility and acquiescence may not have their voices well represented in the focus group discussion (Keahne and O'Connell 2010). This can become more problematic where the study involves a sensitive topic, sensitive experiences and personal matters (Wimmer and Dominick 1997). According to the NSF (1997), focus group interviews are inappropriate where there is such sensitivity, it inhibits people from talking openly and where the depth of individual responses is what is mainly required as can be facilitated in semi-structured interviews.

DISCUSSION OF DATA COLLECTION METHODS FOR THIS STUDY:

This section presents the chosen method of data collection for this study, namely, semi-structured interviews and states the advantages of employing this approach. Here the PWLD are seen as the experts in experiences of their own oppression. The practitioners working with them are seen as people who have direct and regular contact with PWLD. This places these practitioners in pivotal positions to provide an 'outsider' view of the oppressive experiences affecting PWLD.

Kvale (1996) defines a qualitative research interview as a professional dialogue between the interviewer and the research participants aimed at extracting rich data about a phenomena under scrutiny. For Miller and Glassner (2004) interviews are the means through which the researcher can access and explore the meanings people attribute to their experiences. This essence of interviews is summed up by Kvale (1996:5-6) in the statement: "the main purpose of the interviews is to obtain descriptions of the life-world of the interviewee with respect to interpreting the meaning of the described phenomena".

Four key advantages of using semi-structured interviews for this study were identified:

Firstly, semi-structured interviews allowed flexibility in questioning, sequencing of questions and in catering for the different communication needs of the respondents (Britten 1995; Ryan, Coughlan and Cronin 2009; Berg 2009). In the process, the researcher will build on this flexibility to clarify or provide explanations of the meanings of the research questions. Also, it is the flexibility needed by the researcher to pursue ideas raised by the respondents in more detail, to clarify meanings during the interview (Kvale 1996; Berg 2009) and which enabled participants to bring about issues or ideas the researcher had not thought about. According to Smith (2007), this flexibility offered by semi-structured interviews provides the participants with

maximum opportunities to tell their stories in their own words and from their point of view compared to use of questionnaires.

Secondly, due to the learning difficulties experienced by participants, face-to-face contact was an important way of communicating ideas. This is considering that many have difficulties with reading and writing. The use of mail surveys, for example, would be problematic in that PWLD may have difficulties filling these in. Chances are that they will seek help from carers, professionals or service provider staff members to respond on their behalf. Responses may not reflect accurately on the participant's experiences or opinions (Baxter 2005). Participants may not feel comfortable to disclose certain experiences to the staff members further limiting the quality, quantity and the completeness of data.

Thirdly, face-to-face semi-structured interviews allowed the researcher to establish rapport with participants, in particular participants with LD who are prone to developing anxieties in such circumstances (Savenye and Robinson 2006; Knox and Ward 2009). According to Knox and Ward (2009), establishing rapport is the means through which trust is built and maintained that the participants can feel at ease to openly share their personal experiences during the interview. As pointed out by Bogdan and Biklen (1992) interviews can be successful when the participants feel at ease and free to disclose their life-world to the researcher.

Fourthly, face-to-face semi-structured, interviews also provided the interviewer with the opportunity to observe participant's non-verbal communication which was useful and in some ways: serve as a means of observing whether there is a match between what the participants are saying, their emotions and their body language. This can provide some clues about whether participants are being truthful or not (Jones and LeBaron 2002); and non-verbal cues can assist the researcher in identifying different signs and symptoms of distress, behavioural difficulties and mental states relevant for the on-going assessment and monitoring of participant's well-being during the interview (Ryan, Coughlan and Cronin 2009).

Finally, PWLD often have difficulties understanding complex information, words, pictures or symbols (Baxter 2005, Mencap 2000) and face-to-face interviews allows for opportunities to clarify questions, words or phrases. But also, the researcher will be able to verify whether the participant with learning disabilities has understood the question so as to obtain more honest and accurate responses. Importantly, the semi-structured questions should allow the participants to

describe their experiences, some of which can be sensitive, in their own words in order to get closer to their real world of experiences, emotions and thoughts about oppression (Office of Disabilities issues 2011). Probing and going beyond the superficial meaning will be difficult to achieve using structured questionnaires with PWLD (Cederbog and Lamb 2008, Baxter 2005).

DISCUSSION OF THE INTERVIEW GUIDE USED:

Designing of the interview guide was an important first step in the interview process. The guide consisted of the following four main topic areas: 1) Nature of oppressive experiences of PWLD; 2) The impact of oppression of PWLD; 3) The strategies employed by PWLD to cope with their oppression and 4) The likely causes of the oppression of PWLD. Guided by these research questions, the questions and probes of the guide were derived from the modified questions from already existing research instruments, most of which are specifically for PWLD.

The set of guide questions on the nature of oppressive experiences were derived from a mix of questionnaire instruments by different authors. This included the research instrument designed by Mencap (1999) for its survey study on bullying and harassment of PWLD and Stephenson (2009) on their survey on hate crime, bullying and harassment. Other examples involve the instruments by Cummins (1997, 1993) which has questions for PWLD about their material well-being, productivity, place in community, safety and their satisfaction in different life areas. Aspects of Schalock and Keith (1993) questionnaire regarding competence/productivity, empowerment/independence and social integration/community proved to be essential in developing questions on family life, amount and usefulness of education, employment, and community inclusion. Further ideas were borrowed from a questionnaire by Melley et al (2010) in their report study on the developmental studies for the National Adult Social Care User Experience Survey. They used helpful questions about what PWLD experience was good or bad about their quality of life, how they are treated and how they feel about their social lives.

Questions on the impact of oppression on PWLD were derived mainly from quality of life questionnaires. These included questionnaires by Cummins (1993, 1997) and Schalock et al (1990) which looked at satisfaction of PWLD in terms of: material well-being, health, productivity, intimacy, safety, community and emotions. Also helpful was the revised domains of quality of life by Schalock (2004) which highlighted specific questions on self-identity, social networks and contacts, financial status, employment status, personal development including educational achievements, self-determination (autonomy) and human rights of PWLD.

Furthermore, Staniccliffe and Parmenter's (1999) choice questionnaire offered some important ideas on the kind of questions to ask regarding the issues of overall control of one's life and exercise of choice among PWLD.

On formulating questions on prevention strategies, some information and ideas were obtained from Malley's et al (2010) research tool for PWLD. For example one of their questions (If worried or unhappy about something what will you do? was useful in trying to find out what actions PWLD take to prevent or cope with oppression. Equally relevant were the questioning techniques derived from Wilson, Seaman and Nettelbeck's (1996) interview schedule for a study on vulnerability of PWLD to exploitation. Such techniques involved asking questions specific to forms of oppression raised by the research respondents as in these examples; What did you do when they: teased you, shouted at you, asked for money or asked you for sexual favours.

Finally, questions on the causes were derived from all the questionnaire instruments and literature mentioned above (nature, impact and preventive strategies). A few questions were adopted from instruments of non-learning disabilities population such as the World Health Organisation (2000) and Office for National statistics (2002, 2008), for their relevance to the research question.

Due to access difficulties, the interview guide for PWLD was not pre-tested with PWLD. However, professionals (not experts in the area) had the opportunity to read through the interview guide to give 'face value' feedback about whether it was good or not. The general consensus among four individuals involved was positive and recommended input from experts in the area. Hence, a Learning Disability Nurse, went through the guide and gave her feedback. The wording of some questions was changed. A role play with one Learning Disabilities specialist practitioner helped to check the time it was likely to take to complete the interview and to have some idea of the quality of answers likely to be given. Further some checks were also carried out during the peer review of the study by experts in the area of oppression and victimisation research.

CHALLENGES ENCOUNTERED AND HOW THEY WERE OVERCOME:

Throughout the data collection process, major challenges were observed in the following two areas: 1) Establishing rapport and 2) in the actual administration of the semi-structured interviews.

Establishing Rapport:

Establishing rapport with all participants and in particular PWLD was key to the effective conduct of semi-structured interviews without which thick descriptions of oppressive experiences among PWLD could not have been achieved. Knox and Ward (2009:570) posit that the researcher-participant relationship is the cornerstone of qualitative face-to-face interviews. Similarly, Alder and Alder (2002) perceive this relationship as one of the single most important ingredient of a qualitative research study on which data collection is based and trustworthiness of the findings relies. The willingness of the participants to freely disclose personal and sensitive information about their life experiences depended heavily on the quality of this relationship (Knox and Ward 2009; Alder and Alder 2002). Therefore it becomes essential that rapport with potential participants is established right at the first contact and to be built and maintained throughout the duration of the research period (Kvale 1996; Ryan, Coughlan and Cronin 2009). Spradley (1979:78).

Establishing adequate rapport is particularly important when entering a research relationship with vulnerable people such as PWLD. Many PWLD may lack self-esteem, have anxiety problems, limited life experiences and many have little or no control over their lives (DOH 2001) that they may lack trust of other people and inhibited in their participation due to the balance of power in favour of the researcher (Walmsley 2004). It then becomes the researcher's responsibility to create a relationship based on mutual confidence, respect and acceptance (Sattler 1992). Once rapport has been established and maintained, it should help combat anxieties, help participants to be at their ease while sharing their experiences with the researcher, reduce the feeling of intrusiveness, and provide a strong foundation for the study (Munford et al 2008)

Based on these benefits of rapport in the study, a substantial amount of time was devoted to establishing rapport with PWLD in order to ensure that the quality of this research relationship was sound. This was achieved through telephone conversations with participants and mainly face-to-face encounters where research and non-research related topics were discussed. Although it was disclosed to all participants that the researcher was a nurse, it was made clear that this was purely a research relationship which had to be maintained as such throughout the study. This was important as many PWLD may lack social networks and their social contacts are mainly with professionals rather than with members of the public (Pockney 2006). Researchers coming into

their lives could be seen as “providing opportunities for social connection, the chance to talk to someone new and to be listened to for a time” (Munford et al 2008:341). With similar views, Stalker (1998) adds that there is the risk of being perceived as a friend and depending on the length of the study or contact, it can become difficult to bring this relationship to an end. Hence, it was essential to define the researcher’s role at the start and then continue to monitor the relationship throughout the study (Pockney 2006).

Establishing rapport with practitioners was equally important as with PWLD. This was essential considering that the research project addresses a sensitive topic about the oppressive experiences affecting PWLD and the practitioners may distrust the researcher’s motives for conducting the study. This could be that the practitioners themselves can be seen as part of the system that oppress PWLD (Northway 2000) and may not feel comfortable to participate. But more problematic was the fact that the study was being conducted at a time after the BBC panorama programme, which exposed the mal-treatment of PWLD at Winterbourne View Hospital. To gain the trust, the researcher met with each practitioner at least once before the interview to familiarise with each other and to discuss as well as to clarify the purpose of the study.

Administering the Interviews:

Between October 2011 and January 2012 11 volunteers with a diagnosis of learning disabilities and 11 staff members who support them were interviewed about oppressive experiences affecting PWLD. The interviews lasted between 40 to 70 minutes for PWLD and between 60 to 90 minutes for the support staff members.

All respondents were interviewed at places of their choice and familiar to them. Some were interviewed within premises of their organisations and others at their own homes. These were places where the participant will easily find and travel with no difficulties. In that location, the most quiet and more relaxed room available was used. Elwood and Martin (2000:649) point out that interviewing people at places of their choice and where they feel comfortable does not simply help in creating an atmosphere conducive to conversation, but will also be an additional step in addressing the researcher-participant power relationship. The authors argue that by undertaking interviews at Universities, the researcher might be seen as a figure of authority or expert which in one way or the other may affect quality of the data the respondents may be willing to share.

Before the start of the actual interview, time was devoted to prepare each respondent for the interview. It was important to find out from the respondent whether they were still willing to take part in the project and to be audio recorded. It was also an opportunity to remind them about their role in the study. Here, emphasis was placed on reminding all respondents about the boundaries highlighted in the information sheet with regards to what can or cannot be disclosed. Considering the issue of concentration span and communication difficulties in PWLD (Baxter 2005), the choice of how people wanted the interviews to be undertaken was provided. This included choice to have breaks, undertake the interview in more than one day and whether they needed carers or support staff to be present (Nind 2008; Dalton and McVilly 2004). Furthermore, it was necessary to find out from the individual with Learning Disabilities how they could show that they did not want to continue with the interview or that they did not feel comfortable answering a question.

Once all the necessary respondent preparations were complete, the tape recording equipment was checked for proper functioning. Heritage (1984) points out that recording the interview is essential in qualitative studies considering that thick data is likely to be generated by this type of data collection method. The author argues that due to the issue of recall bias it may not be possible to achieve a complete account of this conversation between the interviewer and the interviewee without audio recording it. Taking notes will not only disrupt the smooth flow of the interview and affect rapport with interviewee but also affect the quality of data collected as reliance on the researcher's memory will not be able to accurately capture the whole interview compared to audio recording (Patton 2001; Bailey 2008). In addition, audio recording the interview has several other advantages which include enabling the researcher to go back to the exact words of the interviewee, allowing thorough examination of the series of exchanges that took place in the interview as well as allowing scrutiny of the data collected and its analysis by other researchers (Heritage 1984:238). In this study all interviews were recorded with participants' permission and hence, for the reasons mentioned, it was important to ensure that the actual recording took place.

Interviewing PWLD was particularly challenging and effort was put to follow the best practice recommended by various experts in the field of learning disabilities. But each individual was unique in terms of their interview needs and the challenge was the ability to be able to draw from these generalised recommendations to effectively achieve a successful interview. While all were quite articulate and with mild learning disabilities, they still had significant limitations in their

vocabulary. Great care was taken to simplify the questions and to adopt the terms and words used by the respondents. For example, instead of using the word oppression terms/words such as bullying, harassment, abused, hate crime or frightened introduced by the respondent were used. The use of such phrases as “treated unfairly” and “made you unhappy” helped the participant to go beyond bullying/harassment and sometimes beyond harm defined as crime.

But it was not enough to just modify vocabulary. It was also important to help the respondents with learning disabilities describe their experiences of oppression at different stages of their lives. The general approach was to start from school age, then young adulthood, employment moving into middle adulthood and the present if they are older people. This was essential in identifying victimisation in different contexts or situations (school, work, home, public areas and institutions). According to Thomson and Fowkes (1999), this cross-referencing of events which involves identification of one event and referencing it to one or more other meaningful events can help respondents to recall some important events.

The use of open ended questions, whether it be the general main questions or probes to pursue issues raised by the respondents with learning disabilities, were key to address problems related to acquiescence and suggestibility as well as allowing respondents to explore their oppression in their own style or approach. However, such questions did pose various challenges to some PWLD. Some took longer to process what the questions were asking them. Practical steps were taken such as making the questions shorter and simpler, repeating the questions and allowing more time to respond. The aim was for the researcher to aide quicker accurate understanding of the questions, achieve maximum focus to the relevant areas of the study within the interview time limits and to ensure the learning disabilities respondents provided the required thick descriptions of their experiences. But where the PWLD seem to have continued difficult answering the question, it was necessary to find out whether it was just lacking of understanding of the question or it was that the person was not comfortable answering the question.

One of the most challenging aspects of the interviews with PWLD was dealing with the sensitive and emotional issues arising from their experiences of oppression. Experiences of sexual abuse, feelings of rejection and narrations of unfair treatment described by respondents impacted emotionally on both the participants and the researcher. One male talked about being sexually abused by boys who left him naked in the cold for several hours. Another respondent with mild learning disabilities described how his wife considered taking his life when their child was taken

away into care and never got an explanation for why this happened. In these examples the participants were visibly upset and an appropriate response from the researcher was warranted. The researcher was aware that he had to maintain the researcher role and could not respond therapeutically at that stage unless it was necessary. In all cases episodes of getting upset were brief and were addressed at the end of the interview. Knox and Burkard (2007:573) highlight that it is essential to separate the research role from the therapeutic role. The author argues that if such separation is not visible that can cause role confusion for participants. In turn, it can introduce biases related to how respondents interpret this confusion and thus impacting on the quality of data collected. Also problematic when listening to the emotional and sensitive issues was the issue of researcher managing his own emotions. Some of the experiences mentioned above are quite disturbing and remaining neutral without showing strong emotional reactions was a challenge for the researcher. While it was difficult to monitor your own body language reactions, it was always at the back of the researcher's mind to avoid any unwanted responses whether through verbal or body language reactions.

Interviewing staff members was on the whole successful as there was great interest in the research topic. Each one of them was able to adequately cover the areas of the interview schedule. The enthusiasm in the participants and their passion in working with PWLD meant that little was needed in terms of encouraging people to talk. Like with interviews with PWLD, there were some challenges interviewing the eleven practitioners. The interviews involved nurses, support workers, a victim support co-ordinator and an advocate who were not only different in professional roles and settings in which they work but also different in their educational backgrounds. The main challenge was to communicate at each individual's level of communication. For example, two of the support workers were not comfortable with the use of the word oppression stating that it was a 'big word' for them and preferred to use such words as abuse, unfair treatment, neglect and other different elements of oppression. It was also important to continuously remind yourself about the role, setting in which the interviewee worked and the contexts of events being described. This was essential for the researcher to understand where the individual was coming from and to then ask the relevant probes or questions.

Other challenges arose where interviews opened up several leads. The researcher had to make quick judgements and decisions about which leads were relevant to the study and to follow with greater depth. This was necessary considering the limited time which was available to cover each topic area of the schedule and the need to ensure that there was some control over the length of

the interview. However, the researcher was aware that allowing people to talk and to listen were key interviewing skills. Effort was put to refrain from commenting or interjecting unnecessarily.

CONCLUSION:

Once the semi-structured interviews were complete a great deal of qualitative data had been collected. The next stage was to draw all this data together so that it could be organised and analysed in a meaningful way (see Chapter 4).

CHAPTER 4: DATA ANALYSIS PROCESS

INTRODUCTION

This chapter presents a detailed account of the processes involved in investigating qualitative data using the IPA data analysis process. Section 1 starts by providing a brief introduction of IPA data analysis highlighting the underpinning assumptions of the process; Section 2 considers the range of data analysis methods that could be employed; and Section 3 sets out the procedures and details the analysis processes followed. Tables, mind maps and interview quotes will be used for better understanding of key issues emerging from data and transparency purposes.

IPA DATA ANALYSIS PROCESS:

The semi-structured interviews generated a vast amount of data and this needed to be organised, summarised and transformed into new knowledge following a clear and logical process. This was necessary for purposes of transparency and making it easier for the evaluations and comparisons of studies on the same topics (Astride-Stirling, 2001). For this study, the IPA data analysis was the method of choice.

Smith (2007) defined the IPA data analysis process as a qualitative process that enables detailed exploration of the meanings and views people ascribe to their own experiences through in-depth examination of transcripts of their accounts of events. The analysis is based on thematic analysis a method used for identifying, analysing and reporting patterns or themes within a set of data (Smith, Flowers and Larkin 2009). The analysis is data driven requiring sustained engagement of the researcher with the text. This is in line with its idiographic approach, which places emphasis on the particular and on the distinct experiences of individuals. The researcher should be committed to understand as much as possible from one research respondent before moving on to the next respondent (Reid, Flower and Larkin 2005:10).

Also, IPA data analysis process should enable the researcher to move from the particular to the shared (Reid, Flower and Larkin 2005). According to Cassidy (2010:06), this is an acknowledgment that the individual's experiences have both a unique and a shared context. Hence, cross-case-analysis across groups of respondents should help to develop a balanced understanding between what is shared (the general) and what is distinct of the individual (the particular) (Reid, Flower and Larkin 2005). This involves searching for common themes, establishing patterns and integrating these in a way that helps in focusing on the important issues arising from the data.

A high degree of transparency is essential throughout the analysis process to ensure plausibility and transferability of any IPA study. The use of diagrams or tables and particularly verbatim quotes is critical in achieving this transparency.

WHY OTHER METHODS WERE PROBLEMATIC:

When considering a way in which to approach the analysis of the voluminous qualitative data collection from the research, the following were considered: Grounded theory, thematic analysis and narrative analysis.

Grounded Theory:

The aim of grounded theory is to achieve the conduction of an effective and rigorous qualitative study. Its goal is to generate theory that is grounded in data. While it shares some similarities with IPA, it was not the most ideal method for this study. This is mainly due to the reasons highlighted by Willig (2008:73). The first reason is that grounded theory is more concerned with the study of basic social processes with a focus on identifying and explicating contextualised social process that account for phenomena. While, on the other hand, IPA aims to gain a better understanding of participants' and their subjective worlds with a focus on the nature or essence of the phenomena which is more relevant to this study. The second reason, highlighted by Willig (2008), is that there are now several confusing debates and controversies about grounded theory which the researcher will have to engage in before choosing the appropriate theory to use. This was not going to be convenient considering the limited duration of the study.

Thematic Analysis:

Braun and Clarke (2006:06) define thematic analysis as a "method for identifying, analysing, and reporting patterns (themes) within data". It is not theoretically bounded that it can be compatible with many research methods. It is this lack of specificity and the adaptation of a general approach to analysis of all qualitative data which made the method less suitable for this study. The approach may not be able to achieve the required rigour which methods such as IPA, tailor made to analyse people's subjective life experiences, can easily accomplish. In particular, it is the idiographic feature of IPA, not expressed in thematic analysis, which may make a difference in the quality of data, variations between individuals and findings of the study in general.

Narrative Analysis:

Narrative analysis share significant commonalities with IPA in the sense that it also focuses on human experiences and assumes that these experiences are best understood from the person's perspective (Riessman 2008). However, narrative analysis differs from IPA in that its emphasis is on the sequence and coherence of thoughts, experiences and events of a story as the basic way humans make sense of their own lives (Clandinin and Rosiek 2007). Thus, attention is focussed on identifying segments of narratives or themes which can be plotted linearly having a beginning, middle and end to make connections or links that provide a logical framework for comprehending human experiences (Hancock, Ockleford and Windridge 2009). The method can be more effective where the purpose of the investigation is to explore sequences, chronology, patterns or life changing events at individual level (Gibbs 2011). But in this study, the focus is on meaning of what research respondents experience in their daily lives. Hence, IPA which is tailor made to provide systematic processes of extracting units of meaning from data, is the ideal data analysis method of choice. It is committed to understanding the content and complexity of meanings through identifying themes or units of meaning in words, phrases, sentences and paragraphs in order to comprehend the uniqueness of each individual (Smith 2007). Unlike narrative analysis which is not concerned with moving beyond the individual (Clandinin and Rosiek 2007), IPA also seeks to understand the interviewees' shared experiences necessary for the potential transferability of findings of this study (Clandinin and Rosiek 2007).

WHY IPA IS APPROPRIATE FOR THIS STUDY:

The main goal of this study is to achieve a better understanding of the oppressive experiences affecting PWLD living in the community. The aim of IPA to explore in detail people's experiences, and how they make sense of their experiences becomes directly relevant to this study. Its idiographic approach should help with fine-grain analysis of each participant's account of his/her subjective world to achieve the anticipated depth of understanding of the negative life experiences of PWLD. Importantly, IPA also allows for the development of insights into experiences unique to individuals and contexts, and those experiences common to the social group under investigation (Smith 2004), which is essential in this attempt to see the bigger picture of the difficulties faced by PWLD.

But it is its connectedness with the interpretative philosophical stance, phenomenological design and the semi-structured interviews employed in this research project that facilitated its selection as the data analysis of choice. Its foundation is underpinned, among other philosophical theories, in the interpretative or hermeneutics traditions that emphasise in meaning and understanding

(Smith and Osborn 2007). According to Biggerstaff and Thompson (2008) semi-structured interviews are an important means of producing the required dense data that they are almost always used together with IPA. The requirements for small samples, the appropriateness in dealing with complexity, providing rich descriptions and allowing an active role of the researcher in collecting as well as interpreting the data (Finlay and Ballinger 2006) are all shared by the IPA approach.

IPA PROCEDURE:

The general consensus among authors is that there is no definitive way of undertaking IPA data analysis and that it will be inappropriate to provide a prescriptive framework for IPA (Brocki and Wearden 2006; Smith 2004). However, there is common need to undertake a systematic search for experiential themes, establish links between themes and to formulate superordinate or major themes that best capture the main issues identified by the respondents (Smith and Osborne 2008). This can be best achieved through a cyclical process in which the researcher systematically and insistently follows a number of graded stages that ensure rigour in the scrutiny of each participant's interview and the shared experiences (Biggerstaff & Thompson 2008:11). In this study, the analysis process was undertaken following the six stages suggested by Biggerstaff & Thompson (2008): 1) Familiarisation with data- Transcription and Reading transcript; 2) Identifying preliminary themes; 3) Grouping themes as clusters and Tabulating themes in mind map or table; 4) Repeat stages 1 to 3 with subsequent interviews; 5) Drawing all themes together and 6) Grouping themes found into super-ordinate themes.

Stage 1: Familiarisation with Data Stage:

Transcription:

Wellard & McKenna (2001) pointed out that transcription of the audio recorded interviews should be an integral part of the data analysis process and should not simply be taken as a clerical task. Hence, each of the twenty two audio recorded interviews was transcribed verbatim which enabled the completion of the research participants' responses in greater detail. In many cases, this meant listening to the audio recording several times in an attempt to capture the exact exchange of verbal communication during the interviews. Response tokens such as OK, Yeah and Hmm were retained as they provided insight into the nature of the conversation and content of the interview (Oliver, Seovich and Mason 2005). Involuntary vocalisations such as laughing and raising voices in anger were also noted down to reflect the emotions involved and the extent to which the matter being discussed were important to respondents.

It has to be acknowledged that where some non-verbal communications made it more difficult to follow conversation threads (e.g. regular hand gestures) or are judged to be of no relevance (e.g. sneezing and sniffing because the person had cold) were removed from the transcripts. On the request of the respondent to represent some of his responses in a sensitive manner, some words, phrases or language used were cosmetically modified. For example, on the issue of sensitivity the researcher respected the respondent's wish to erase some of the descriptions of the treatment he received from his father. He was happy for a modified version of this description to appear on the transcript but without the very unpleasant words he used to describe his experiences.

Transcribing was carried out by the researcher as it is important to recognise this as a valuable part of the data analysis process. Had the task been contracted out, then a great deal of experiential evidence only available to the interviewee would have been lost. This, according to Halcomb and Davidson (2006:39), was an essential part of the on-going processes of bringing the researcher closer to the data gathered which is a critical aspect of the IPA data analysis. But also, this ensured that the transcripts, which the readers will use to judge the interpretations made in this research project, are sympathetically edited and accurately reflected the meanings and perceptions shared in the interview conversations.

Reading Transcript

Smith (2010) refers to this as an essential analysis stage that introduces deeper understanding of the data that should enable a sound examination of the descriptions, meanings and interpretations shared by respondents during the interviews. The focus of this stage was to ensure that the researcher became inordinately acquainted with the data collected. To achieve this, the researcher was involved in an intensive and iterative process of reading and re-reading each individual transcript. The researcher became actively engaged with and intensely immersed in the data, in the process familiarising with some central concerns, coherent meanings, complexities and subtleties of the data (Storey 2007:52-53). The researcher made notes of any observations, thoughts or emotions about what is happening in the data and where necessary, made comments or even asked questions of this data (Swanson and Holton III 2005). Attempts were made to internalise as much of the information as possible (Braun and Clarke 2006) in order to be able to reflect on the overall meaning emerging from the data (Srivastava and Thomson 2009). For example, at the end of familiarisation stage of Transcript 02, the researcher had some awareness that respondent PWLD did not like attending a SEN school. Also, that he

was bitter about the way he was treated at work and by his own family, in particular by his father. These became some of the initial labels around which preliminary themes were developed.

Stage 2: Identifying Preliminary Themes:

Once familiarised with the data, each transcript was analysed in great detail in an effort to achieve a rigorous exploration of idiographic subjective experiences. Smith et al (2009) suggests that this is the commencement of a thorough critical analysis and an advanced step in making sense of the usually thick data. At this stage of the transcript analysis, the researcher went through the data in more detail undertaking a line-by-line examination to identify meaningful qualitative experiential incidents that seemed to reveal experiences of oppression which appeared to be repeated at different points throughout the interview (Chenail 2012). These units of analysis were organised through codes and sub-codes or tags according to the issues, patterns and themes emerging from the data. Codes and sub-codes or tags could be in the form of key words, phrases, paraphrases, sentences, headings, descriptions, explanations and labels that best capture experiential descriptions, concerns and understandings of each research respondent (Biggerstaff and Thompson 2008).

For example, on analysing PWLD 02's interview transcript, some themes were developed because they were repeated in sentences or paragraphs. Words such as 'scared', phrases such as 'put up with it', sentences such as 'I was depressed', the idea that PWLD are not given opportunities and are socially excluded were repeated enough to conclude that they were important experiences/concerns of respondent PWLD 02. Other themes were important because of their tendency to suggest the very typical everyday experiences of people found in their life situations. Examples include: I felt vulnerable, taking the mick out of me, they bullied me, I kept myself to myself, putting me down, no one listens, SEN schools did not prepare me for independent living, I thought of ending it. In addition, personal reflections and other comments about the issues, patterns and themes were noted in the margin and within the interview transcripts. In addition, text not associated with a theme was re-examined and where appropriate they were tagged to existing themes or developed into new themes. See Appendix 08 for a demonstration of how Transcript 02 was analysed. Also see Table 08 for more examples of preliminary themes generated from transcript 02.

Table 08: Some Examples of Preliminary Themes Generated from Transcript 02

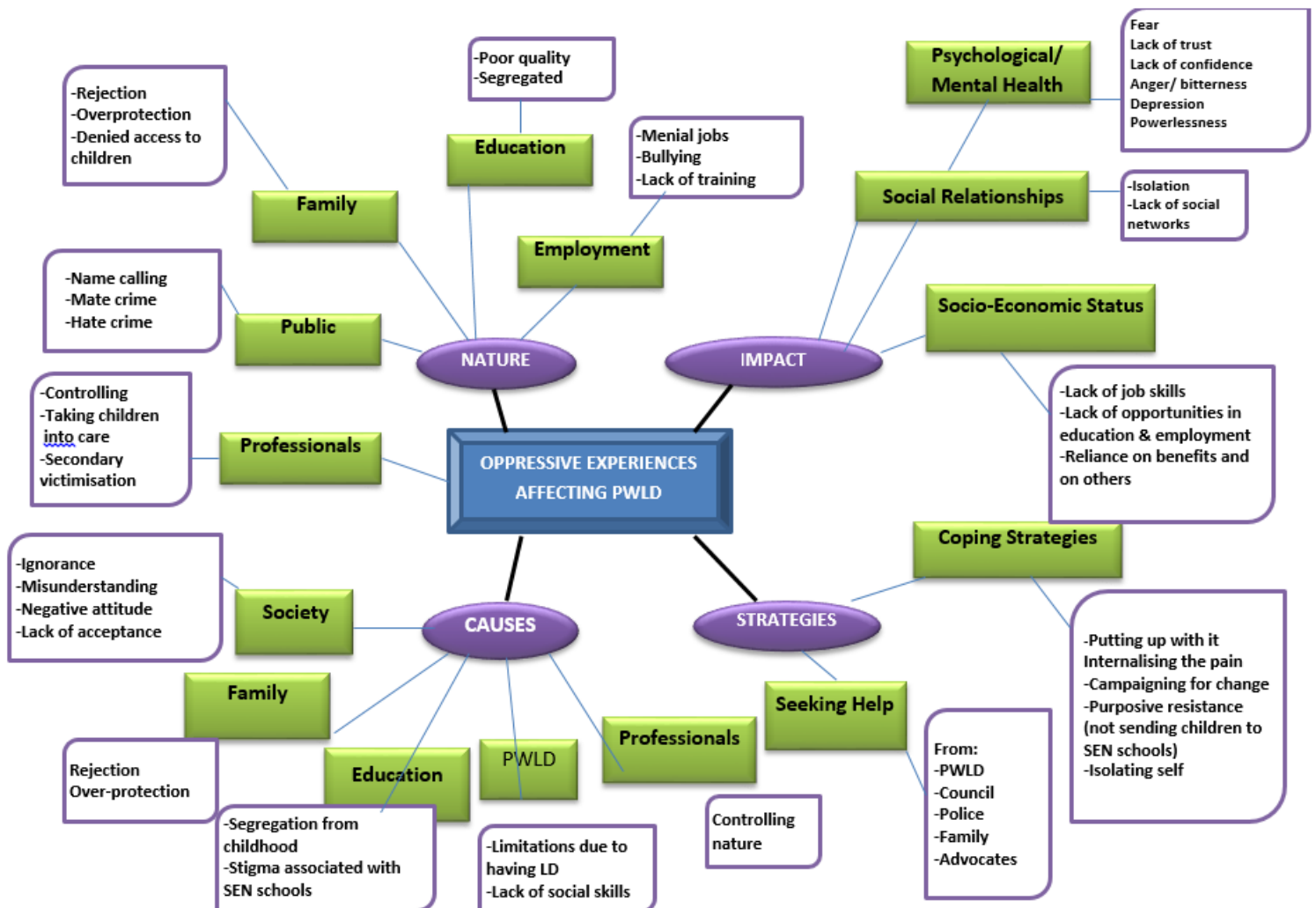
THEMES INTERVIEW QUOTES	EVIDENCE:
Rejection/ unwanted by father	“I was not the perfect first born dad wanted.... I can forgive everybody else for treating me unfairly but not my dad”
SEN schools: Poor quality of education and segregated	“I went to a special school. I did not do much there and it was just a waste of time” “If I was the Government, I will shut down all the special schools and mix everyone in the main schools. That’s where the problem is – we are isolated from the start”
Menial jobs	“That was the worst job I have ever had” “ I did kinds of jobs no one else wanted to do like dusting”
Anger	“I was angry about it, quite bitter”.
Putting up with oppressive experiences	“How I worked there for six years I don’t know..... I could have packed my job in (left) but I had to put up with it”
Isolation	“Here I kept myself to myself really. I did not mix with other people I felt really depressed , I would lash out a lot and felt more isolated a lot more then”
Lack of confidence & fear	“At that time my confidence was not good and was scared to talk to people. ...I was scared of what people could do to me, that people could take advantage of me”.
Over protection by family	“But in the end my brother took over. He got it from my dad and he would do everything for me but I needed to do it on my own”

Stage 3: Grouping Themes into Clusters and Tabulating them in a Mind Map/ Table

Having developed an intimate knowledge of themes generated in stage 2, it was observed that the emerging themes were too many and required further reduction in order to establish a clearer story of oppression revealed by respondents, each case at a time. Hence, at this stage, the connections between themes in terms of meaning, patterns and hierarchical relationships were established. In this process, ideas were reordered, two or more themes were amalgamated, labels

of some themes were modified and new categorises or themes were discovered to formulate a higher order of classification that enabled the researcher to make more sense of the data in a way that answered the research questions. Thus, the four areas of the research instrument (nature of oppression, impact of oppression, causes of oppression and the strategies for coping with individual oppressive experiences became useful broad categorises under which major themes and sub-themes were organised. Categories such as education, employment, public places, family, professionals and institutions emerged as some of the major themes indicating the sources of oppression embedded in these four major areas of the study. In turn, under these themes were sub-codes which described these in more detail. In Figure 02 below are examples of clustered themes and the reorganisation of data that emerged on completing stage 3 of analysing transcript of PWLD 02.

Figure 02: Grouping Themes into Clusters and Tabulating in a Mind Map



Stage 4: Repeat stages 1 to 3 with subsequent interviews

Once the first three stages of the analysis (I to III) were completed with the first interview transcript analysed (PWLD 02), the same three stages were repeated with the second, third interview transcripts and with the rest of the subsequent interviews to the 22nd interview (Practitioner 11). See Appendix 09 for another example of analysis of Transcript 01(PWLD 03) and for its preliminary and clustered themes.

This consolidated the idiographic aspect of the IPA process in an attempt to understand in-depth what was unique to each individual participant. The process is in line with the notion of commitment to a detailed case-by-case interpretation that should allow the research to understand as much about one case before moving onto the next as suggested by Smith, Flower and Larkin (2009).

Stage 5: Drawing together all the themes generated from all interview transcripts

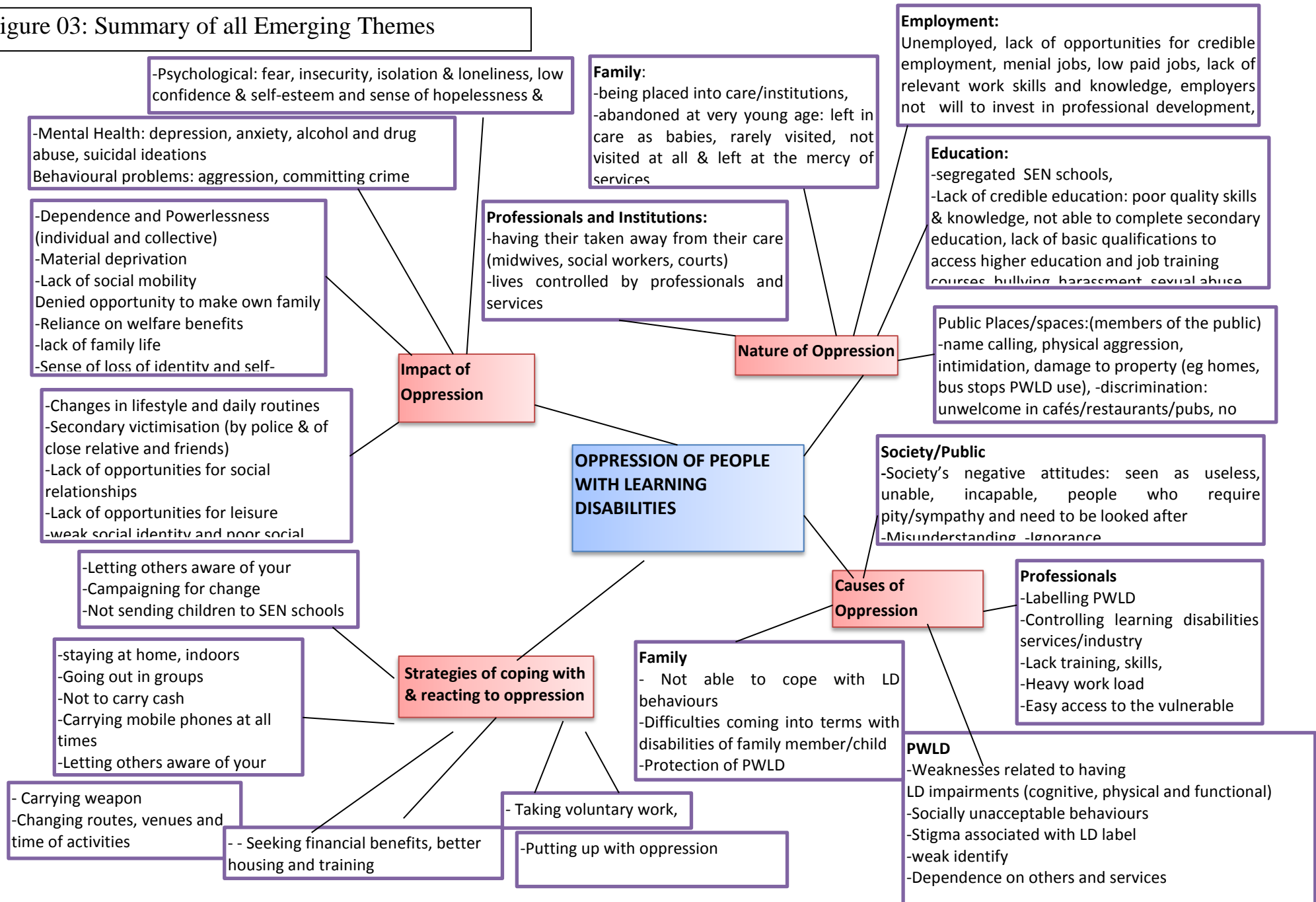
At this stage, all the themes generated from the 22 interviews were drawn and integrated together. This marked a shift from an idiographic mode of enquiry to a more nomothetic interpretation of the integrated data generated from the whole group (Biggerstaff and Thompson 2008). The goal was to be able to produce interpretations which best capture the differences and shared experiences of oppression expressed by the research respondents. For example, a look at themes for Transcript 02 and Transcript 03 show that there are many similarities in experiences of education: they both did not like attending SEN schools; they both did not see the value of the quality of education they received which both believe did not prepare them for the real world. There were also similarities in experiences of employment: they both lacked skills to do better jobs and did jobs they considered not liked by others without LD, they were both bullied and both deeply hurt by these work experiences. But there were also differences, PWLD 02 was mistreated by his own father and over-protected by mother and brother which was not the case with PWLD 03, he had no issues with his family. PWLD 02's main issues were of experiences of employment and education, while PWLD 03's main concern was having his child taken away. See Table 09 for the examples of extracts from PWLD 02 and PWLD 03 for comparison purposes.

Table 09: Examples of Extracts from Transcripts

Themes	Interviewee Comments
Family:	<p>“I was not the perfect first born dad wanted.... I can forgive everybody else for treating me unfairly but not my dad”. (PWLD 02)</p> <p>-“But in the end my brother took over. He got it from my dad and he would do everything for me but I needed to do it on my own” (PWLD 02)</p>
Employment:	<p>“That was the worst job I have ever had”. “I did kinds of jobs no one else wanted to do like dusting” (PWLD 02)</p> <p>“I had good parents really, a nice family” (PWLD 03)</p> <p>“I got my first job when I left school. I got finished after 3 days. I could not keep up with other workers” (PWLD 03)</p>
Education:	<p>“If I was the Government, I will shut down all the special schools and mix everyone in the main schools. That’s where the problem is – we are isolated from the start” (PWLD 02)</p> <p>“I went to a special school. I did not do much there and it was just a waste of time” (PWLD 02)</p> <p>“I also felt that the school was not teaching me the right things. It never prepared me for the world of work” (PWLD 03)</p>
Parenting:	<p>“My ex-partner used to have a lot of power. She always got her own way. She did not want me to see my kids. (PWLD 02)</p> <p>“They took our child away. We tried everything we could possible doto try to keep him”. “The issue with my child has taken over everything. It is the number one thing at the moment” (PWLD 03)</p>

Drawing all themes together was another opportunity to re-examine closely the clustered themes for each individual transcript to ensure that all of these themes were represented in the summary table of themes for all research respondents. See Figure 3 for the summary of all the themes generated from the research data.

Figure 03: Summary of all Emerging Themes



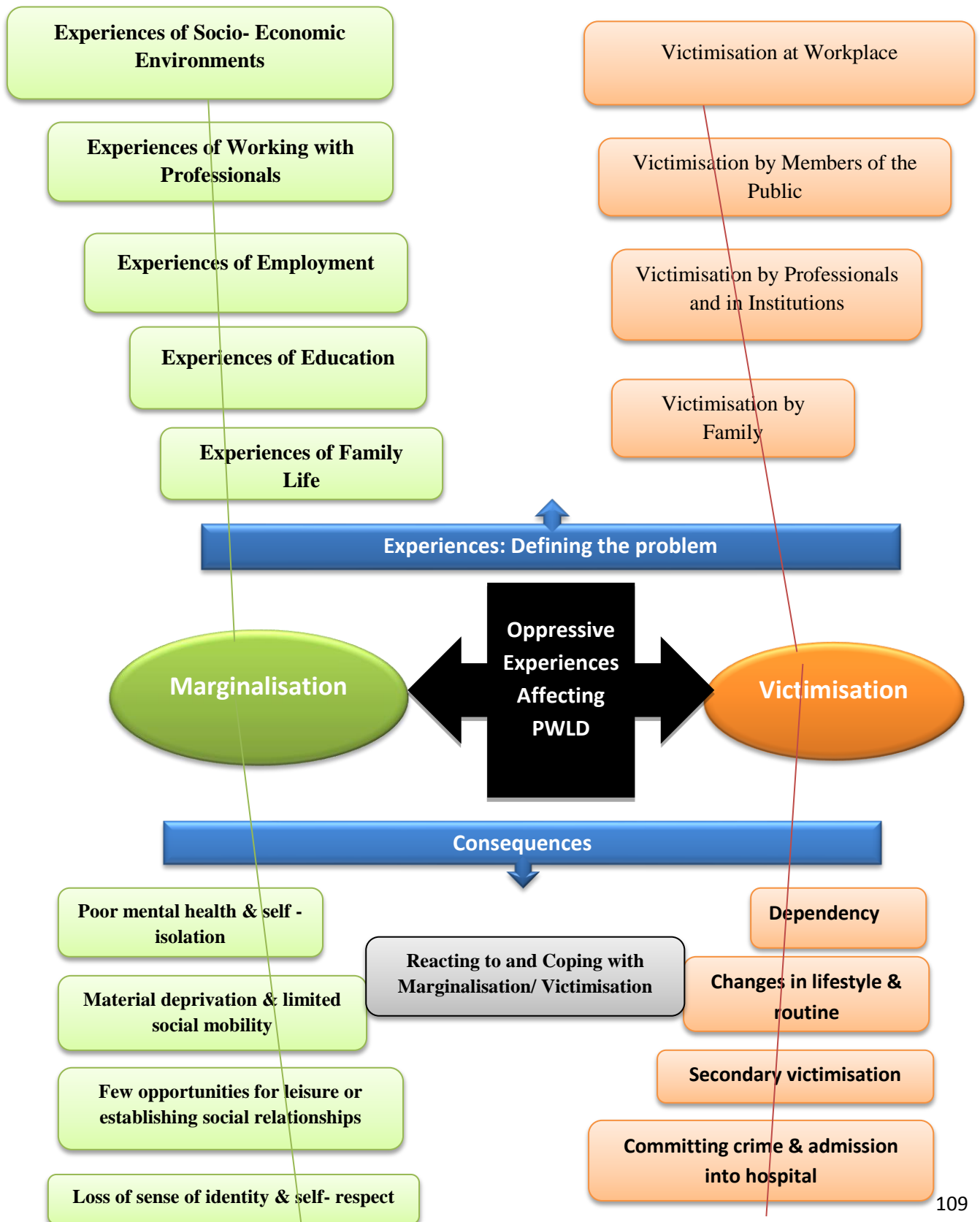
Stage 6: Grouping themes found into super-ordinate themes

This is the final stage of the analysis procedure and aims to define the master or super-ordinate themes to show the bigger picture of the respondents' stories.

The emerging themes were many and quite complex with tendency to indicate a wide range of forms of oppression. Considering this complexity it was worthy drawing from the current frameworks of oppression in order to produce an analysis that is more credible and useful to our audience. Young's (1990) framework of oppression: Five Faces of Oppression was utilised. It was then essential for the researcher to continue asking himself questions suggested by Storey (2007:56): 'Is it in the text?' and 'Where in the text does it say this?' to ensure that themes generated continued to reflect respondent's views and experiences emerging from the data. Hence, of the five faces (marginalisation, exploitation, powerlessness, cultural imperialism and violence), nearly all the themes could be categorised into the Marginalisation and Violence faces. Then, the violence face was widened to Victimisation in order to accommodate the remainder of the themes which did not fit into the narrower definition of violence. Thus Marginalisation and Victimisation became the main types of oppression affecting PWLD. See Appendix 10 which demonstrates the process identifying from the table of emerging themes the various ways PWLD are marginalised. See Appendix 10b for a table showing a summary of these sub-themes of marginalisation. Appendix 11 shows the process of identifying the victimisation theme and Appendix 11b presents a summary of these in a table. Figure 04 below shows a diagrammatic summary of the super-ordinate themes and sub-themes of the study.

On completion of this analysis process, the findings of the study were very clear and these are presented in Part 3 Chapters 1 to 4.

Figure 04: Superordinate Themes



Individual Powerlessness

Psychological, mental health & behavioural problems

CONSIDERATIONS

INTRODUCTION

Social/ Political Powerlessness

considerations involved in the study and the procedures that were put in place to ensure that the research respondents were protected. These will be organised in six ethical areas which will be discussed in the following order: 1) Voluntary participation; 2) Informed consent; 3) Potential risk for harm; 4) The benefits of the study to research participants; 5) Privacy, confidentiality, anonymity and retention of research data.

VOLUNTARY PARTICIPATION:

According to the World Medical Association (2010), participation in all research must be voluntary and there should be no use of coercion, deception or manipulation. The researcher should then take all the necessary steps to ensure that potential research participants clearly understand that their participation is voluntary and that they are not under any obligation to take part (Polonski 2004). In attempts to achieve this, both PWLD and Practitioners were invited to take part in the study via letters. The study invitation and information sheet clearly emphasised that participation was a voluntary choice and it was their right to refuse to participate without having to face any consequences (Appendix 01 and 03). Even when they accept to participate, they were made aware that they could withdraw their participation at any time without giving a reason of their decision to pull out. Davidson (1995) points out that this clarity regarding voluntariness is even more relevant when dealing with vulnerable people such as PWLD who might not understand that getting involved is a personal choice and might feel obliged to please those in positions of power.

GAINING INFORMED CONSENT:

Freely given informed consent is a legal and ethical pre-requisite for potential participants to take part in a research involving human subjects (RCN Research Society 2011). This is understood to be an essential form of respecting the individual's autonomy to decide whether or not to participate in research as well as a process to protect their safety and rights (McDonald and Kidney 2012; Horner-Johnson and Bailey 2013). Gaining informed consent in this study followed the guidance given by the RCN Research Society (2011) that a valid informed consent should involve provision and discussion of research information to potential research participants; ensuring that the potential

research participants understood the information given; ensuring that participation is voluntary and, where possible, obtaining evidence of consent particularly where this involves vulnerable adults. This process was on-going to ensure that research participants were still willing to be involved throughout the study.

Provision and discussion of research information:

This was part of the process where all potential participants were given the fullest possible research information. According to Horner-Johnson and Bailey (2013), this was essential to ensure potential participants had full awareness and understanding of the: purpose of the study; what was expected of them; all foreseeable risks, discomforts and possible benefits, length of the study, who to contact about the research and their rights to decline or withdraw from the study. For potential participants with learning disabilities, provision of information was done in two ways. One way was through an information sheet, which was the written permanent record of the research information approved by the University's Ethics Committee. This provided a summary of the study and a clear outline of the research process in a language accessible to most PWLD. Simple and plain English, pictures, short sentences, smaller paragraphs and bigger font were used based on recommendations mainly by Dalton and McVilly (2004), Lennox et al (2005), Nind (2008) and Department of Health (2010). The information sheet was given to each individual to take away so that they could go through it at a time of their convenience, get support to understand the information from others of their choice and to have the opportunity to consider their participation without pressure.

Another way was through discussion of the information given. According to the National Research Ethics Service (2011), informed consent is more than just provision of information and rated discussion of information as the most effective means to ensure that consent is informed. Discussions were done in small groups and on a one-to-one basis. In small groups, potential participants were met at each host's agreed venues. While this might have some disadvantages which may include inhibiting participation of the less confident, this provided opportunity for a shared understanding of the study (Fraser and Fraser 2001). Potential participants learnt from each other's contribution and asked questions which they might not have asked in individual meetings. Throughout these discussions, potential participants got the support from other PWLD, advocates and carers to express their ideas, to ask questions and to show the extent to which they understood the information given to them about the study.

Discussions on a one-to-one basis were to ensure that the provision of information was tailor-made to the specific needs of the individual (Horner-Johnson and Bailey 2013). This involved considering the person's level of understanding, communication problems and how best to convey the message and specific research issues the individual wanted to be addressed or clarified. This helped in identifying appropriate approaches that enabled the individual participants to achieve maximum understanding such as repetition of the same idea, use of pictures and getting support from carers or advocates where necessary (Wiley et al (2007). Potential participants had the opportunity to ask questions, some of whom had their questions written down in advance.

Providing information to practitioners was also through the information sheet and one-to-one discussions. Information sheets were sent by email prior to meeting with the individual and adequate time was given for them to read through it. Each professional had the opportunity to discuss the study in more detail and had the opportunity to ask questions to clarify issues arising from the information sheet. Their answers to their questions were given as fully as they can possibly be done.

Ensuring that the person understood the information given:

Ensuring the person understood the information was part of the discussion process tackled separately for clarification purposes. This is in line with Mental Capacity Act 2005, which recommends that the researcher should take every step to help the individual understand the relevant information given to them, check for understanding and to be certain that the individual is competent to make a decision.

According to Horner-Johnson and Bailey (2013), checking for research understanding can be critical in PWLD considering their intellectual and communication impairments. In their study in which they assessed the extent to which PWLD were able to answer the questions about key aspects of the study, more than half were able to answer the questions. Hence, a significant number were not. Another study by Arscott, Dagnan and Kroese (1998) showed PWLD can understand some of the information and fail to understand some of the information. As a result, they may end up signing the consent form without full awareness of what the study entails. Therefore, to ensure potential participants with learning disabilities understood the key details and implications of participating in

this study, a series of simple and short open-ended questions were asked. Such questions included finding out if the person could tell the purpose of the study, what the research was about; what the risks and benefits were, what their rights are and how they could communicate their withdrawal if they wished to discontinue their participation. Questions were also asked to find out whether each individual fully understood that they had no obligation to take part in the study and that they could withdraw at any time and without any consequences. In the process the individual had to demonstrate their ability to retain information through repeating and/ or paraphrasing what had been said and to apply the information to their situation.

Ensuring that participation is voluntary and consent is freely given:

Voluntariness to participation was central to the process of gaining informed consent. From the start, it was explained to all potential participants that they had the right to decline participation and to withdraw at any time without giving a reason. And that the decision to participate must wholly be theirs. For PWLD, it was emphasised that declining or withdrawing would not compromise the quality of services/care, intervention or support they received. Considering that power differences between the researcher and vulnerable people may make it difficult for PWLD to decline participation, carers and advocates who knew the PWLD were involved throughout the process (with permission from PWLD concerned). This was an attempt to get help with identifying the unspoken expressions of reluctance to participate from the people who knew them better (Wiles et al 2007).

Also, a gap of about three weeks or more (if needed) was allowed to pass between date information giving and date of deciding to consent to take part in the study. According to McDonald and Kidney (2012) such a gap was necessary to ensure they were not under any pressure or duress from anyone to make any rushed decisions. This gave them sufficient time to think about whether they wanted to participate, ask questions and for PWLD to consult with carers, advocates and families before they could make a final decision (Dalton and McVilly 2004).

Evidence of Consent:

All the practitioners and PWLD (assessed as having capacity to consent) who agreed to participate in the study were asked to provide written consent using a consent form approved by the University Ethics Committee. Participants with learning disabilities signed the consent form (Appendix 02) in

the presence of a witness. The witness and researcher signed the same form in the presence of the research participant. For practitioners, only signatures of the potential participant and the researcher were required on the consent form (Appendix 04), no witnesses were involved. Both the researcher and each participant retained a copy of the signed form. According to Wiles et al (2007), such evidence can be important to help protect the researcher from later accusations by research participants and/ or carers (Wiles et al 2007).

It will have to be acknowledged that the role of the keyworkers who acted as gatekeepers in the process of selecting participants with learning disabilities could generate a complex power dynamics which may impact on consent. However, access to participants was only through these gatekeepers who had the power to allow or deny them to participate. It is noted that without them there would have been no opportunity to gain access to the participants and subsequently no opportunity for them to take part in the study. With regards to those who participated, there was no evidence that suggested that they were being coerced to consent. For those who did not participate, there is a potential that they were denied participation. These people may be oppressed differently, for example, they can be more marginalised or victimised compared to those who participated in the study. Hence, there is the potential that findings would not fully reflect their experiences.

POTENTIAL RISKS FROM HARM:

The likely potential harms:

There was the potential for participants to be adversely affected psychologically and/or emotionally because of their participation in this study. Psychologically, this could involve developing signs and symptoms of depression, anxiety, fear and getting distressed during and after the interviews. Emotionally, there was the potential for participants to get angry or upset, tearful or exhibit behavioural problems.

Overcoming the potential harm:

The researcher took a series of measures which could help to avoid or reduce the impact of the distress caused by taking part in this study. One way was to pre-warn all respondents of the risks involved and this would serve as a means of preparing them psychologically for the expected eventualities (Baxton 2005). Also, effort was made to ensure that questions were worded in a way that did not cause unnecessary distress and allow the respondent to define the problem in their own terms. In addition, it was made clear that where the respondents found the questions distressing

they were free not to answer the questions or to stop the interview if necessary. Furthermore, the researcher would use his clinical skills to identify any signs and symptoms of distress, anxieties or unwillingness of respondents to proceed with the interview by carefully listening and observing of verbal and non-verbal languages before, during and after the interview. Follow-ups were made with respondents, organisations and keyworkers days and weeks after the interviews to ensure that no harm occurred as a result of participating in this study.

For PWLD extra protections were put in place. This included ensuring that adequate rapport and research relationship had been established before the interview could be administered. The researcher was made aware of any issues of concern affecting any of the potential respondents and advised of the strategies used by respondents to cope or deal with their distress in order to arrange for the relevant supports before the interviews. This included being prepared to use basic counselling skills to support participant within one's sphere of competence and to ensure that keyworkers known to the person were readily available to provide support when required. The potential respondents would not have taken part if they had been unsettled in behaviour and mental state in the past four weeks. All respondents were interviewed in places familiar to them to reduce anxiety. It was made clear and emphasised that no new experiences of victimisation were to be disclosed. According to McNulty and Wandle (1994), increased psychological or traumatic symptomatology is likely to occur during new disclosures compared to disclosures of what is already known.

For both practitioners and PWLD, any adverse consequences were to be recorded in line with usual organisational reporting policy. A report was to be sent to the supervisor and ethics committee. The organisations' counselling services were to be used at times of distress. Where such services are not available, respondents were to be referred to victim support services such as VOICE UK and RESPONSE who are experienced in dealing with victims with learning disabilities. Contact details of these organisations were provided on the information sheet.

THE BENEFITS OF THE STUDY TO RESPONDENTS:

This was an opportunity for respondents to exercise their right to participate in research that addressed their needs (Holland 2008). Gilbert (2004:298) highlights the dangers of protectionism and losing sight of the empowering potential of being involved in research and having a voice in

matters that affect them. According to Tuffrey-Wijne, Bernal and Hollins (2008), it may be seen as unethical to exclude from studies PWLD who have capacity and are willing to participate on the basis of 'vulnerability'. This is a historical assumption about learning disabilities which has resulted in reduced opportunities for them to collaborate in research. This has negated the opportunity for PWLD to fully share their experiences on a range of topics affecting their lives (Dickson- Swift, James and Liamputtong 2008).

It also has to be acknowledged that talking about distressful events is not always detrimental to the mental state of individuals. According to Dickson-Swift et al (2006) and Johnson (2009), a significant number of research respondents find involvement in sensitive or emotional related research beneficial, valuable and therapeutic in the sense that it often provides a sense of catharsis. The cathartic benefit has been associated with experiences of comfort, validation, empowerment as well as having the unique opportunity to confide in someone interested and caring and to be able to openly vent out their emotions (Tillmann-Healy and Kiesinger 2001). Hence, the question is not about whether to involve them or not when they voluntarily decide to take part, but a question of how best to involve them with minimised risks.

PRIVACY, CONFIDENTIALITY, ANONYMITY AND RETENTION OF RESEARCH DATA:

All information provided by participants will remain confidential within the limits of the law and in accordance with Data Protection Act (1998). Throughout the study, including in the final report, respondents will not be identifiable. All respondents' interview responses will be forwarded directly to the chief investigator and data will be coded to remove identifiable information soon after the interviews. All information that identifies their name, address and other personal details will be replaced by a numerical code number. Subsequently, all information generated from the interview will be linked to this numerical identity code in addition to being completely anonymised. Certain comments may be quoted or paraphrased in the final report but no identifiable information will be provided. Where details can be linked together to affect anonymity information will be further broken.

Audio recording used will be kept safely in secure University lockers/cabinets and all data collected during interviews will be stored on secure password access computers in locked rooms. Access to the information will be restricted to the chief investigator and with participants' permission the

researcher's supervisory team may request to have access to the data for teaching and learning purposes but with no means of identifying respondents. All data from the research will be destroyed after 5 years.

The research project was undertaken under the guidance of the Coventry University principles and standards of conduct on governance of research which were designed to ensure that all research activity is conducted to the highest levels of integrity.

CHAPTER 6: REFLECTIVE PRACTICE

INTRODUCTION:

The aim of this chapter is to reflect on the role of the researcher and how the researcher- respondent relationship impacted on data collection and data analysis in an effort to enhance transparency, accountability and trustworthiness of the study. The chapter is organised in five sections: Section 1 discusses the dilemma on whether or not to disclose the researcher's nursing background; Section 2 examines the researcher-respondents' power dynamics and its influence on data collection; Section 3 explores the problems arising from dealing with issues that presents occasions of conflict of whether or not to offer therapeutic intervention; Section 4 reflects on the wider impact of the study and Section 5 provides a brief summary of the key lessons learnt from this qualitative research project.

DILEMMA: WHETHER OR NOT TO DISCLOSE THE RESEARCHER'S NURSING BACKGROUND

The Nurse-Researcher role conflict was felt before data collection, becoming evident at the time of deciding how to introduce myself to the respondents, in particular, those with a diagnosis of learning disabilities. At face value there did not seem to be any concerns about introducing myself 'as learning disabilities nurse to undertake a study on the oppression of PWLD'. But on stepping back and examining the issue from a researcher's standpoint, it was clear that presenting myself as a nurse could affect the researcher-respondent interaction in a number of ways. Firstly, there was the possibility of the Nurse-Researcher to be seen as part of the system that oppresses PWLD, which can discourage opening up or even the actual participation in the study (Northway 2000). Secondly, being perceived as part of the system could also make potential respondents feel compelled to take part in the study and this is against the principle of voluntary participation. Thirdly, if any of the

respondents had previous negative research experiences with Nurse-Researchers, this could introduce discomfort or anxieties which in turn could negatively impact on the quality of data generated and results of the study (Colbourne and Sque 2004).

However, I was also aware that revealing his nursing background could bring some positives to the study. It would seem that respondents associated or related themselves with me as a learning disabilities nurse and may have questioned less my motives for conducting research with and about PWLD. In turn, this may have facilitated their participation in the study (Colbourne and Sque 2004). The same sentiment of relating or associating (with respondents) was felt by the researcher himself. This added to that sense of feeling at ease which was essential in the establishment of rapport with research participants (Dickson-Swift, James and Liamputtong 2008). At personal level, the idea of not disclosing my nursing background was difficult for just any previous contact with learning disabilities nurse may have been negative and I did not want this to hinder my research relationship.

For the purposes of mutual trust and informed consent, I decided to be honest with research respondents by disclosing my nursing background from the outset. It is a role I am familiar with, which seemed to have connected me with respondents and made me feel at ease with them. This was key to establishing the required rapport and trust generated in this study. But it was made clear to respondents that my primary role was to collect data on the oppressive experiences affecting PWLD and not to offer nursing interventions.

RESEARCHER- RESPONDENT POWER DYNAMICS

Having disclosed my nursing background and current research student status, I was cognisant of how these professional and institutional positions could create power imbalances with respondents and in turn on the quality of data and results of the study (Jack 2008). The feeling of power was located in the professional (nurse) and institutional (Coventry University) positions I occupied. I thought about how these could be seen as positions that can impose authority and power which could make it harder for respondents to refuse to participate. I could be seen as exploiting powerless vulnerable people for academic and research purposes (Arber 2006). Steps were taken to ensure that respondents gained some control of the research process and their participation to reduce some of the power imbalances. This was through giving the choice of dates, time, venue and whether

respondents wanted to do the interview once or spread over a number of days (Ritchie 2009). During the interviews, I did not lose sight of the fact that the purpose of the study was to understand the life experiences of PWLD from the respondents' perspective without any form of coercion. Hence, I refrained from imposing my own views on respondents through questions which allowed respondents to focus on their experiences (Dickson-Swift, James and Liamputtong 2008). This involved questions with phrases such as "can you tell me about your experiences....", "How did you feel about that?" Further probes were used to help respondents go back to some key moments of their past experiences and to facilitate deeper analysis of these experiences in their own words.

I felt it was also empowering participants the fact that the research questions covered matters respondents felt were of great importance to their lives. It would seem it was in itself a major driving force in wanting to participate in the study and willingness to share some of their private, personal and sensitive experiences. Devastated by having his child taken away from his care, PWLD 03 found the study an opportunity to voice something which had a deep impact on his life. Hurt by experiences of attending SEN schools, PWLD 03 indicated in his statement that he wanted to discuss his experiences beyond the current hate crime discourse: "it is not only about hate crime, but it is about our way of life" which is under attack. This shift from the dynamics of power to the locus of empowerment may be seen as an important aspect in influencing the quality of data and the results of the study.

However, it has to be highlighted that the balance of power was not always in my favour. This was evident at the time of waiting for the potential respondents to confirm whether or not they were going to participate in the study. It was all up to the potential respondents to decline or agree to participate and there was not much I could do. Once confirmation was made for participation, there were fears that respondents could lose interest in the study and drop out before and after the interviews. Furthermore, I felt that sense of powerlessness located in my identity of being a migrant and student. There was the potential of being perceived as uninfluential, with no ability to effect the changes expected by the respondents, hence, the danger of not being taken seriously (Das 2010).

DEALING WITH SENSITIVE ISSUES: WHETHER OR NOT TO OFFER THERAPEUTIC INTERVENTION:

Melville (2011) defined sensitive research issues as those that focus on emotionally difficult topics, delve into deeply private or personal experiences, involve vulnerable groups and likely to have serious consequences to research participants. The study focused on an emotionally difficult topic: 'Oppression as experienced by PWLD' and the interview questions, which provoked psychological or emotional responses from both the respondents and the researcher.

Psychological or emotional responses from research respondents ranged from feelings of frustration, anger, to feelings of being overwhelmed by their experiences. For example, one respondent showed his frustrations about the way his life was being controlled by professionals. PWLD 10 got upset when he talked about the way he was unfairly treated at a pub and how he was physically abused in prison. Detailing how he had been overwhelmed by his loss, PWLD 03 expressed how losing his child 'had taken over everything' and nothing else mattered in his life except wanting to be reunited with his child.

Here the challenge I faced was on making decisions about if, how or when it was appropriate for me to react therapeutically to the respondents' emotions. This was made more complicated due to the lack of clarity in literature on this matter. For some authors there was emphasis on maintaining research integrity (Lipson 1991) and for others the well-being of respondents always takes precedence over maintaining research integrity (Jack 2008). But Colbourne and Sque (2004) points out that in such events untangling the researcher role from the nursing role can be difficult. For the authors it is better to use the nursing skills rather than trying to hide them. Hence, they suggested the use of both nursing and researcher skills to minimise the respondents' psychological distress, to assess the levels of harm being caused and to make decisions on whether to intervene or not. Meanwhile, effort should be put to adhere to the research protocol and steps taken to ensure a more accurate data collection.

I was aware of the influence therapeutic interventions can have on interview responses such as change in focus of interviews, discouraging opening up, premature termination of the interview (Jack 2008:60). I drew up some measures to minimise this. In line with the ideas of Colbourne and Sque (2004) stated above, the interview questions were carefully formulated and asked. In all cases there was no need for immediate intervention and any basic emotional support given was done at the end of the interview. In addition, I made follow-up contacts with gatekeepers, key workers and

respondents themselves to confirm the state of the mental health and well-being of respondents. This was all to ensure that integrity of the study was maintained and the health, dignity and rights of the respondents were respected at same time.

It has to be acknowledged that there was an underestimation of the impact the respondent's disclosures could have on the researcher. The researcher felt uneasy with some of the disclosures, in particular those that involved exploitation, sexual abuse and attempts to commit suicide. It was also the depth of the meanings respondents gave to their experiences, which caused some emotions. As a measure, soon after completing transcribing a transcript, I gave myself time and space to read it and check for any further emotional reactions. This was an attempt to delineate between what was actually said by the responded and how I felt about it (Mauthner and Doucet 2003). This was essential in trying to separate my emotions from respondents' perceptions of their experiences (Arber 2006). Additionally, discussions with my supervisor were useful in coping with such disclosures.

THE WIDER IMPACT OF THE STUDY:

I was largely influenced by the notion of giving a voice to a marginalised group with learning disabilities. Without a learning disability myself, I believed that PWLD and those who look after them were the people best able to reveal what it is like to be oppressed with Learning disability. This was not a simple exercise of passively narrating past experiences. It was an exercise of providing the respondents with the opportunities to interpret their voice, that is, to actively give meaning to their experiences. Thus, they contributed in producing a better understanding of their life situations. This was important to ensure that meanings derived from the individual experiences were not entirely my reflection as an academic researcher. I then explored further these meanings to gain deeper insights beyond factual and the self-interpretation accounts given by respondents (Pringle, Hendry and McLaffety 2011). Using my conceptions, I tried to make sense of the respondents' interpretations of their social world, what Smith and Osborn (2008:53) referred to as double hermeneutics. Here, my learning disabilities nursing background and other life experiences were important aspects of the process I used to understand respondents and the social world I share with them (Balls 2009). From the results of the study, it is clear that a complex web of interconnected socio-economic forces underpin the oppressive experiences PWLD face. It is hoped that this study will help raise the awareness of these difficulties.

LESSONS LEARNT:

My influence as the primary instrument of data collection and data analysis as well as my role in making decisions throughout the study cannot be over-emphasised. These decisions I made and the close research relationships I established with respondents meant that I was not a mere observer but an active player contributing to the research process. These close relationships characterised by mutual trust and respect were central to the success of the interviews. Hence, it was essential for me to be aware of how my roles, assumptions, behaviours, preferences, strengths and weaknesses impacted on the research process, the phenomenon under study and the results of the investigation.

PART THREE: FINDINGS AND DISCUSSION**INTRODUCTION:**

The purpose of the study is to gain a better understanding of some of the oppressive experiences affecting PWLD. The goal of part three is to discuss the findings of this empirical study against the background of existing knowledge centred around Young's (1990) 'Five Faces of Oppression' framework. The discussion will be organised into three chapters. Chapter 1 will use evidence from this study to argue that the original form of oppression marginalisation is not only confirmed but also modified to redefine this form of oppression. Chapter 2 will challenge Young's framework by subsuming the remaining forms of oppression (exploitation, cultural imperialism, violence and powerlessness) under a more integrative term: Victimization, which accurately represents the voices of respondents of this study. Chapter 3 takes a broader overview of the new interpretation of oppression as principally defined by marginalisation and victimisation. On the basis of the research data the chapter suggests the underlying theoretical explanations (internalised oppression, structuration, power-relations and underclass) that may help account for the existence of oppression as experienced by PWLD.

PART THREE: FINDINGS AND DISCUSSION

CHAPTER 1: MARGINALISATION AS A FORM OF OPPRESSION

This chapter aims to discuss key findings on the experiences affecting PWLD that confirm and contribute to modify Young's (1990) notion of marginalisation as a form of oppression. The chapter will be divided into 2 main sections. Section 1 will focus on how the reported experiences from this research data translate into and support this by augmenting the 5 key elements of marginalisation originally suggested by Young namely: a) Long-term paid employment; b) Lack of access to basic resources; c) Severe material deprivation; d) Dependence and lack of autonomy; and e) Lack of recognition and social relationships (Young 1990).

Section 2 will show how the research data adds to and supplements the original constituents of marginalisation identified by Young. This study will argue that lack of credible education and deprivation of family life should also be considered as key elements of this form of oppression to provide a rounded picture of experiences of marginalisation disclosed by the research respondents.

Marginalisation as suggested in Young's framework of oppression:

Young (1990) defined marginalisation as a socio-politico-economic phenomenon in which individuals and social groups are systematically excluded from useful participation in society and thus denied opportunity to fulfil themselves as human beings. The author points out that marginalisation is often seen as a Third World countries' phenomenon. But in reality, it is also common in developed nations such as the United Kingdom where a whole category of people including PWLD are permanently confined to lower standing in society. In this definition, marginalisation is identified as multi-dimensional and the major form of distributive injustice whose ramifications can be felt in every aspect of the lives of those affected. Young places lack of economic participation at the heart of marginalisation and describes the marginalised people as those characterised by the following key experiences which will be discussed throughout this section: **1) Long-term exclusion from paid employment:** Here the study will highlight that while the association between long-term unemployment and marginalisation resonated well with most respondents' experiences, this challenges Young's idea in that the problem of marginalisation is not simply a matter of being excluded from the labour market. The few PWLD who are in employment have continued to fit into the definition of the marginalised due to other factors such as the type of job and their associated wages; **2) Lack of access to basic resources:** This section focuses mainly on how PWLD lack the means to change their lives. Particular attention will be given to lack of skills, training and lack of means to influence change; **3) Severe material deprivation:** This will be discussed as a key consequence of both lack of adequate income and inability of PWLD to move

out of their marginalisation status; **4) Dependence and lack of control:** In this section, dependence and lack of control are discussed as the inevitable and interconnected consequences of marginalisation. Exclusion from employment and lack of access will be highlighted as key determinants. **5) Lack of recognition and social relationships:** The section will show that the consequence of marginalisation goes beyond material deprivation to further impact on the already damaged social relations between PWLD and the communities where they live.

LONG-TERM EXCLUSION FROM PAID EMPLOYMENT:

In this study employment will be defined as the state of being in paid role within an open competitive labour market (including self-employment) where the employee/worker dedicates a certain amount of time in using his/her skills and knowledge to meet the needs of the employer. The reward or pay they receive can become an important source of income to meet their living costs (Beyer and Robinson 2009). The evidence suggests that it remains the most valued activity and key resource of welfare of society which many people, including PWLD, would aspire as a major life goal (Beyer, Melling and Kilsby 2012). According to Humber (2013), for many PWLD, paid employment can be perceived as an important measure of worth and more so, as a means of addressing an ideological burden which they carry of the idea that they are in some way morally deficient. They believe inclusion in paid work provides the opportunity to prove society wrong.

The findings of this study confirm Young's (1990) notion of marginalisation which holds that long-term exclusion from paid employment is a major determinant of oppression which leads to multiple disadvantages and relegation to marginalised social status. According to the author, a central consequence of such exclusion is the sense of uselessness where the affected social group is unable to provide for themselves and/or contribute to society. Such groups are at a greater risk of poverty, having weakened social ties and being locked into a chronic cycle of dependence on others and social welfare benefits. Respondents of this current study revealed that the majority of PWLD are not in employment and many have never been in any form of paid work in their lifetime. This is shown in the following extracts:

- "I looked for jobs but could not get any. Employers did not see my potential. I could not go on like this...." (PWLD 10).

- “I am not employed at the moment. But I do voluntary work...” (PWLD 03).
- “I am 27 years old and since I left school I have never worked. I was not good at school and I don’t think I will ever get a job” (PWLD 05).
- “I never worked in my life and only did some voluntary jobs to help out other people with learning disabilities” (PWLD 01).
- “Many PWLD I have worked with are not employed” (Practitioner 04).
- “The number of PWLD employed is so low. And also the type of employment PWLD tend to get is of low nature as well (Practitioner 02).

These experiences of PWLD being completely excluded from employment are supported in literature. In revisiting the progress made between 1997 and 2010, Melling, Beyer and Kilsby (2011) concluded that not much has changed in terms of the total number of PWLD in employment. A review of literature by Beyer and Robinson (2009), which informed the recent Government Paper: Valuing People Now (DH 2009) on supported employment, was commissioned due to the concern that there is little progress in getting PWLD into employment. This ties in well with the PALS (2006) survey in Canada which found that PWLD were 6 times more likely than others to have never worked. This is also reflected in the employment statistics by The Foundation for PWLD (2011) which estimated that in 2010/11 only 6.6% of PWLD were in some form of paid employment. Overall, these estimates paint a bigger picture of a social group excluded from productive participation or contribution in economic life as suggested by Young (1990).

While these unemployment rates are so elevated, it has to be highlighted that many PWLD want to work and are out of work not because they do not want to (Humber 2013). The key question to ask becomes: Why are these unemployment rates so high? As reiterated by respondents of this study and reported in literature, an important reason is that of societal negative perceptions towards this social group. Many in society still assume that PWLD cannot work because they have learning disabilities. PWLD 03 points out that they are “not even given a chance to prove what they can or cannot do”. The assumption is “PWLD cannot learn” and are not employable. This is the fact despite the existing and growing evidence that PWLD can be successfully supported to fit into the

world of paid employment. For example, a Scottish study (Ridley, Hunter and Infusion Cooperative 2005), which looked into the employment support available for PWLD, concluded that with the right support in the right job for the individual, PWLD can secure employment in a wide range of jobs that match their individual preferences and employers' needs. In their study jobs PWLD undertook included being car park attendants, cleaners, store assistants, housemaids, salespersons, hotel receptionists and jobs in office administration. Similarly, Practitioner 10 in this current study reported working with PWLD who are employed part-time by Sainsbury's supermarket as cleaners, shelf stackers and till operators. According to the practitioner, "they are paid the same pay as any other Sainsbury employees who do the same job as theirs". Many have been rated as reliable, hardworking and consistent workers (Ridley, Hunter and Infusion Cooperative 2005). They are better off financially which reduces their dependence entirely on welfare benefits (Beyers and Robinson 2009).

Apart from this prevailing ideology of un-employability of PWLD, Humber (2013) identified as key causes the practical problems with the ways: PWLD are prepared for work in schools and Further Education institutions; work is made available and PWLD are supported to find work. Taking the issue of preparing PWLD for work, the author found that Further Education courses are becoming an end to themselves and losing their relevance in providing the required work skills. The colleges are seen as an alternative social service where PWLD might enrol because they do not have anywhere else to go and there was evidence of students with learning disabilities moving from one college to another. This becomes the reality that many will not have the necessary work related skills and as a result are shunned by the labour market. In turn, this can reinforce the doubts employers have in the ability of PWLD to meet their demands. On the problem of how PWLD are supported into work Beyers, Melling and Kilsby (2012) reported that there is not enough range of specialist employment support programmes to cater for the wide range of training needs of this heterogeneous group. Most support is provided to those who need less training support and many PWLD with higher support needs are being left out, yet the programme was originally set up to support such people. This combination of factors may explain the reasons why despite the rhetoric about the importance of PWLD getting into paid work, little has changed in terms of their employment rate since the 1990s (Humber 2013).

But it is clear from this study that the few PWLD in employment have remained marginalised and facing economic hardships. This challenges Young's idea which emphasises the existence of marginalisation as a problem for those outside the labour market, in that the problem of marginalisation cannot simply be a matter of whether one is included or excluded from paid employment. The evidence in this study shows that PWLD in employment were doing part-time, menial and low paid jobs which did not improve their social standing in society. For example, PWLD 02 described his job as:

- "That was the worst job I have ever had and how I worked there for six years, I don't know. I even did a lot of over time doing work no one else wanted to do like dusting" (PWLD 02).

Describing his pay, PWLD 04 expressed that:

- "It was like being paid a slave wage. They paid me £5.00 for working the whole day".

Here a whole social group of PWLD is being excluded from a credible and substantial share of the open labour market and confined to menial low paid jobs. The extent of this problem has been highlighted in various other international studies. For example, O'Brien and Dempsey (2004) compared employment services available for PWLD in Australia, Finland and Sweden and found that employment of PWLD in low skilled jobs remains problematic in the developed countries. Based on their findings, PWLD have continued to be attracted to jobs such as packaging, woodwork, sewing, assembling and cleaning which they described as some of the lowest paid. Similar findings were reported in a Scottish study (Ridley, Hunter and Infusion Cooperative 2005) and by Beyers and Robinson (2009). Although evidence from the literature indicates that other PWLD in work are being paid the same pay as the non-disabled employees and are considered better off financially, there is no evidence that they have moved out of the marginalised status. While they may not rely entirely on welfare benefits for income, they still find security in this income and other welfare subsidies such as housing and transport (Melling, Beyers and Kilsby 2011). Here the main issues are the exclusion of PWLD from high skilled jobs due to lack of relevant education and skills training and difficulties in securing higher rates of pay and more hours in work, as opposed to the problem of total exclusion from the labour market as suggested in Young's framework (Ridley, Hunter and Infusion Cooperation 2005).

Young's notion of marginalisation can be further challenged and criticised for ignoring the difference between economic and social marginalisation. This is based on the evidence both in this study and the literature showing that many PWLD are in unpaid or voluntary work. While they may be economically marginalised, they may not be socially marginalised as voluntary work can provide them with opportunities to contribute to and engage with others within communities. In addition, it provides them with that sense of worth and self-esteem, and enhance their opportunities to get into paid employment. The extracts below show some of the wide range of voluntary activities PWLD are involved in:

- "I never worked in my life and only did some voluntary jobs to help out other people with learning disabilities" (PWLD 01).

- "I am not employed at the moment. But I do voluntary work talking to children in schools and talking to professionals at conferences so that they know how they should treat people with learning disabilities" (PWLD 03).

- "I only work un-paid here as a support worker I consider myself to be doing work for the good of the country. I am doing something, contributing something and there are many people without learning disabilities who do nothing at all but lazing around" (PWLD 06).

Other studies have found similar findings. For example, a two year study of six Supported Employment Agencies in Liverpool found that 8 of the 21 participants were in unpaid jobs (Social Care Research 1996). In a more recent study carried out by Chris Milner (2005) on the employment issues of young PWLD in Tynedale, of the 46 PWLD interviewed only 2 were in paid employment and the rest were doing voluntary work. The National Statistics and NHS Health and Social Care Information Centre (2005) indicated that on the whole 1 in 20 PWLD are in unpaid jobs.

While there are some positives in voluntary or unpaid work such as gaining skills, enhancing self-esteem and opportunity to spend time constructively, voluntary work can be problematic if it is long-term as was the case of PWLD 02 (Grant 2008). The many years in voluntary/unpaid work did not increase his chances of being in paid work. Based on Young's notion of being excluded from labour, experiences of long-term unpaid work can become another form of limiting people's ability to provide for themselves and confining them to rely on welfare benefits. Abbas (2012) believes

that in addition to missing out from this empowering role of paid employment, PWLD's contributions in unpaid/voluntary work will go largely unrecognised by the general population. This in turn can reinforce the notion of uselessness and the maintenance of cycle of marginalisation among this social group (Young 1990).

To improve the employment rates of PWLD, Beyers and Robinson (2009) found it essential that employment of PWLD be seen as part of their life at every level (family, care services, schools, colleges). This should be clearly reflected in compulsory and further education curriculum, in care service packages and transition from compulsory education to supported employment programmes. The authors suggested more investment in expanding the range of specialist supported employment programmes to cater for the wide range of support needs in this group. Overall, there is need for an increased commitment to funding, at a larger scale, of the supported employment schemes to ensure more PWLD can have access to these schemes which have so far been limited to a few (Humber 2013; Beyers, Melling and Kilsby 2012). It has also been suggested that government and support agencies work closely with employers who have been successful and benefited from employing PWLD to learn from them and to spread a positive image of PWLD in paid employment. This is important as there are many in society who still doubt that PWLD can work in as wide a range of jobs as the general population (Humber 2013).

Summary:

Based on Young's notion of marginalisation via exclusion from paid employment, it can be concluded that this notion resonates well with the experiences of many PWLD, the majority of whom are unemployed. However, there is also marginalisation within paid employment which Young seemed to have overlooked. Those in employment find themselves in part-time, menial and low paid jobs which have not moved them out of the marginalised status. A lot of work still needs to be done to ensure employment is seen as part of the lives of PWLD and that there are adequate resources to achieve large scale employment of PWLD (including those who have high support needs). Also, it would seem that Young overlooked the difference between economic and social marginalisation among those unemployed. A significant number of unemployed PWLD participate in voluntary work. While they can be economically marginalised via exclusion from paid work, they can be socially included through engaging with their communities. The consensus is that the

necessary resources (financial and human), positive attitudes and reforms in the way PWLD are supported into employment should help change the status quo.

LACK OF ACCESS TO BASIC RESOURCES:

Lack of access to basic resources was another of Young's key elements of marginalisation confirmed by this research study. Young (1990) suggested that marginalised social groups can be identified through lack of access to basic resources such as formal education, skills and training, employment, participation in voting and in politics and health and social care services. These are resources that promote growth, development and opportunities for progression within the social hierarchy. Young saw these resources as the everyday practical means without which the oppressed cannot move out of marginalisation as individuals or as a generation. The evidence emerging from this study shows that PWLD are a socio-economically disadvantaged social group with very little or no means to help them overcome these disadvantages:

- “It is about our way of life which is the main problem. Our life experiences leave us in a position where we are not able to cope with life or look after ourselves” (PWLD 02).
- “It is not all about bullying or mate crime but also about our ways of living: being able to look after ourselves and coping with our lives ourselves and getting good jobs will make a big difference to our lives” (PWLD 01).

PWLD are not only able to describe the state of their lives and to identify what change is needed, but also to identify that they haven't got the means to make the changes required to improve their lives. There is a huge sense of being trapped, living a life which Fyre (2000) described as being caged in and confined by barriers that block all avenues. They would like to get 'good jobs' which they believe will make a big difference to their lives. However, their 'way of life' is characterised by a combination of poor quality of education and lack of work related skills and training in post-secondary education, needed in order to compete for jobs in the open labour market (Humber 2013). This will be discussed in detail under the education section.

Apart from education and employment issues, respondents identified participation in politics and government as important resources they are being denied access to. They believe that having

political influence is critical for achieving successes in changing attitudes and empowerment of PWLD:

- “I think we need to see PWLD in positions of power and in government. They will be good role models for PWLD. This can help to change attitude towards PWLD by the general public.... I think that way people without learning disabilities will respect us more and that is what I think” (PWLD 02).

On the issue of lack of access into politics, Barnes (1991) suggests that involvement in the political process is considered one of the hallmarks of citizenship. Lack of such involvement can lead to little or no representation of the interests of the affected social group. The author pointed out that PWLD have since been politically excluded and barriers to their political involvement include lack of accessible information with regards to political debates, difficulties with registering to vote and lack of the actual physical access to polling stations. Thus PWLD are not only left out from contributing on matters that affect them, but they are also denied the empowering benefits voting has on having their voices listened to by politicians.

This can raise the questions about the reality of having PWLD in positions of power and in government; This considers Staniland's (2009) study which suggested that the general population do not feel comfortable voting for PWLD as a member of parliament. Other issues are a lack of credible education, communication problems and difficulties coping under pressure (Mencap 2014). But World Institute of Disability (2005) believe that it is feasible to support people with disabilities into government positions with positive outcomes. In their study, they found that having disabled people who were supported to occupy government positions helped to improve legislations and the situation of the disabled in their respective countries. At times, it was simply their presence in such positions that helped to increase awareness and understanding of disability issues among their non-disabled government colleagues who then joined them to promote the rights and inclusion of people with disabilities (PWD). Similarly, Dearden-Phillips and Fountain (2005) share the same view that PWLD can be supported to participate at such high levels of decision making. This is based on the parliament model project initiative set up in 2000 in Cambridgeshire. The parliament is made up of 23 MPs with learning disabilities selected by peer. Cabinet ministers specialise in an aspect of care and support needs. Monthly meetings are held in which MPs set the agenda of discussion and chair the meetings with support from a Charity Speaking Up staff. Senior service managers attend and

guests who are able to contribute to issues of discussion will be invited from agencies. Extensive support and training to develop skills and knowledge in areas such as presentation, leadership and learning disabled related issues is given to those involved in this initiative. The influence of this project has been felt within the local learning disabilities services. An example is when the parliament made complaints about the poor quality of services at a certain residential home leading to a series of events, including replacement of the home manager, aimed at promoting positive change at the home. Also, 100 GP surgery receptionists received training in learning disabilities matters after the parliament raised its concerns about the way GP surgeries often treat PWLD (Dearden-Phillips and Fountain 2005:202). Another example is the involvement of PWLD in service review panels in Scotland. Campbell and Martin (2010) who evaluated 15 Health Boards in Scotland reported a successful story of the inclusion of PWLD as reviewers of NHS services in Scotland. Although the initiative will require on-going improvements, it has shown the feasibility of involvement of this client group at such a level, requiring them to make important decisions about their life needs.

Even if there are doubts about the feasibility of participating at such high level politics and in government, Mencap (2014) argues that at least they should be supported to exercise their basic right to vote in general and local elections. In their recent study, they showed that the difficulties with voting highlighted by Barnes in 1991 have not changed. The survey reported that although most PWLD want to vote, many cannot vote because they find the process of registering difficult and a significant number are turned away from voting because they have learning disabilities. Access to such an essential shared community resource should help with their empowerment as citizens and not simply as service users.

While the voice of respondents with learning disabilities was strong in areas of education, employment and politics, lack of access to healthcare was raised mainly by practitioners. The practitioners gave a wide range of examples of how PWLD can be denied access. These included: a general practitioner refusing to provide a certain type of medication because it is too expensive and delaying treatment to provide the treatment when it is too late (PWLD 01). Others have given examples of the stories coming out of the media where PWLD have developed complications unnecessarily (Practitioner 07). This is in line with a recent inquiry into a premature death, which found that PWLD die prematurely from causes that could be prevented or treated by accessing good

quality care available to the general population. Hospitals have continued to lack the necessary adjustments which ensure PWLD can benefit from care available as much as other people. As a result, men with learning disabilities are dying 13 years younger than the general male population, with women dying 20 years younger than the general women population (DH 2014). Similar findings had been reported by Hollins et al. back in 1998. They found that PWLD were 4 times more likely to die from treatable or preventable causes of ill-health, and that 58% of PWLD die before they reach the age of 50.

In summary, lack of access to resources is seen by Young as a fundamental mechanism through which PWLD are socially disabled. Society has not made it easier for them to gain the relevant skills and training means through which they could achieve upward movement within the social hierarchy ladder. They are being denied opportunities to exercise their basic rights such as voting and to participate in politics and government. Yet, these are the key resources that should empower them to contribute, make their voices heard and have some influence in matters that affect them and others. However, society has continued to doubt the practicality of PWLD's participation in decision making at higher levels. This is the case despite evidence not only of the feasibility of their involvement but of the benefits of such participation.

SEVERE MATERIAL DEPRIVATION:

With many PWLD unemployed and in low paid jobs, evidence in this study shows that income becomes one of the main commodities PWLD are deprived of. With little or no income at their disposal, respondents highlighted that many PWLD cannot afford to acquire essential personal household property/belongings taken for granted by the general population and struggle to provide for themselves and their families. Below are examples of statements expressed by respondents to describe PWLD's state of deprivation:

- “PWLD survive completely on benefits and can only afford the basics. They cannot afford to buy a house, live as they wish and choose who they want to live with” (Practitioner 06).
- “Members of the public would struggle to cope with life if they were to be put in PWLD's financial position” (Practitioner 04).

- “You have probably noticed that the flat I live has so many cracks and has been deemed inhabitable. But material things or the quality of accommodation is not a priority for me. All I need is a place where I can call my own home” (PWLD 10).

The statement above by PWLD 10, who had experiences of being homeless at some point in his life and of many years of unemployment, clearly shows how PWLD can be severely deprived. Living in a condemned flat, wearing worn out and visibly dirty clothes and still unemployed, he was happy to at least hold on to something which he called his own. In this case, the level of deprivation was so severe that the acquisition of other basic needs became a luxury as the respondent was grateful for the little he had. This reinforces Young’s perception that severe material deprivation is a major consequence arising from being left out of the labour market and lacking the means to access and use basic resources. This provided the visible evidence that identifies PWLD with marginalisation.

Various other studies have highlighted the same problem of severe material deprivation among PWLD. The DWP (2013) in their report ‘Fulfilling Potential: Building a deeper understanding of disability in the UK’, clearly points out that disabled people are more than twice likely to experience poverty and material deprivation compared to non-disabled people. The report also revealed that about 12% of adults with disabilities live in persistent poverty (3 years or more in households below 60% median income) compared to 6% of the non-disabled population. Few are able to buy fruit and vegetables. According to a survey by Emerson and Hatton (2008) a significant number of PWLD could not afford: a holiday, going to the pub or club, a hobby or sport, going out, new clothes, new shoes, telephoning family member or friend, food and heating. Another study focusing on children (Emerson and Hatton 2007), found that children with learning disabilities are more likely to live in poverty and live in households where neither parents are in paid employment. According to Emerson (2009), by the age of 3 about 63% of such children would have lived in poverty.

From evidence of this study and findings by other researchers, it is clear material deprivation is a key feature of their marginalisation. According to Young, this can be seen as a feature that highlights the socially constructed distributive injustice which devalues the sense of worth of the collective identity of PWLD; A feature that defines their overall state of being, which in turn influences how PWLD ought to relate with the rest of society (Pierce 2012). Thus, the broader

picture of their deprivation is reflected by the types of stores they shop at and the kind of material belongings they possess, the kind of jobs they take and the wages they receive. It is also the kind of accommodation in which they live in their adulthood and the kind of public places they go and how they are treated at such places (Barone 1998; Langston 1995). Expressed in a different way, this is reflected by the poor socio-economic status and the overall poor quality of life highlighted by respondents throughout this study.

It can be concluded that material deprivation is not only a consequence of being marginalised, but also an important part of the identity of PWLD that helps to maintain their marginalisation.

DEPENDENCE AND LACK OF CONTROL:

Young (1990) identified dependence and control of the oppressed as the inevitable and interconnected consequence of marginalisation processes. In accordance with this notion, this study confirms that exclusion from labour and lacking access to basic resources can be associated with the dependence of PWLD on professionals and care services. It was evident that without the means by which they can develop and improve their life situations, PWLD have no options but are forced to rely on the state for their basic life needs such as food, clothing and accommodation. Respondents indicated that this dependence was strongly linked to the domineering control they experienced from professionals and services they received. Hence the key issues raised here were: 1) Dependence (in general); and 2) Control, in particular professionals being in control of PWLD's children.

Dependence:

The dependence between PWLD and professionals/services can be defined as a state of reliance in which PWLD are the weaker party not able to influence the other's conduct (Emerson 2004). Respondents' reports indicated that this dependence was profound such that it touched every aspect of PWLD's lives. Some extracts of these reports include:

- "They rely on professionals and care services... It is almost like PWLD are living a service life..." (Practitioner 10).

- “...depend heavily on institutions and professionals who determine their way of life. They rely on welfare benefits to survive, live in service related accommodation and have no say on matters or decisions that affect them” (Practitioner 08).
- “The fact that they have to rely on others for everyday living makes their situation more difficult.... This makes them have little opportunities to exercise choice and to have their voices heard” (Practitioner 04).

Various authors have described these experiences of dependence of PWLD on professionals and institutions. For example, Dowson (1997) suggests that this dependence is part of PWLD’s daily experiences and is bound to continue as long as PWLD are kept away from ordinary lives. The author argues that despite some important benefits brought by deinstitutionalisation, PWLD have remained confined to services and continued to lead their everyday lives as they did in long-stay hospitals. This corresponds well with Power, Lord and DeFranco’s (2012) assertion that current care provision for PWLD has become too standardised and inflexible. In addition, professionals and institutions are unaccountable to the service users they serve, all of which reinforces ownership and medicalisation of PWLD’s lives. These are some of the very subtle processes of marginalising Young (1990) and Harvey (1999) have been urging policy makers, practitioners and scholars to be aware of and understand how they operate in oppressing such vulnerable groups in society.

According to Young (1990) this dependence cannot be eliminated by more welfare benefits. The author argues that welfare benefits only produce further injustice by limiting the rights and freedoms of those who receive them. It will mean being subjected to “patronising, punitive, demeaning and arbitrary treatment by policies and policies associated with welfare bureaucracies” (Young 1990:56). As stated by practitioner 08, the professionals and institutions aided by social scientific disciplines will be the people exercising their power in determining conditions of PWLD’s lives and imposing the rules the dependents have to comply with. Hence, the solution may be in the provision of opportunities for PWLD to contribute to their own well-being and to society in ways that respect them as autonomous citizens.

Professionals in control of PWLD’s children:

As explicit in the arguments above, dependence on professionals and services cannot be separated from the domineering control PWLD experience from professionals and services. The issue of control of PWLD has been raised in policies and various studies. For example, a recent study (Petner-Arrey 2013) found out that support practitioners often controlled PWLD's lives in subtle, pervasive, obvious or overt ways. The study which interviewed 10 PWLD and 10 support practitioners, pointed out that support practitioners became too focused on issues such as safety, health and protection. In the process priority was given to institutional objectives over the goals of the individual person with learning disabilities. In another study of 55 women with learning disabilities from Australia and the Czech Republic, Strnadova and Evans (2011) reported that the main theme which emerged throughout the interviews in both countries was the perceived lack of control these women had over their lives. The similarities in experiences of these women within the same country and between countries serve to indicate how the lack of control over their lives is a widespread issue affecting PWLD.

In this study, there was the sense that this control had overstepped the mark in some aspects of their lives. This was strongly voiced by respondents to highlight an outstanding issue about professionals being in control of children of parents with learning disabilities. Respondents felt powerless having their children taken away from their care and also felt let down by the various professionals including midwives (PWLD 02), the family courts professionals, lawyers and in particular social workers (PWLD 03). They did not have any say in the decisions to do with their own children and did not understand why their children were taken away from them. For some it was like an attack on the rights of parents and children of PWLD as reflected in the extracts below:

- “They took my child just like that....I have not understood why they took our child away from us. They never told us what was bad about our parenting skills. Everybody I have spoken to – not one person has ever said we are bad parents and obviously there is nothing wrong with our parenting. All we heard was a knock on the door by the social worker saying they wanted to take our child away because he needs better than average parents and you are not better than average parents” (PWLD 03).
- “I think the social services took our child simply because we have learning disabilities. It is not a crime to have LD. If it was because we were being accused of abuse, sexual abuse or physical abuse that will be a different matter. But we are simply PWLD who love and want

to be with their children. Surely that is not a crime. So why do you lose your children because you have learning disabilities. We did not have a choice to enter this world with learning disabilities... Me and my wife had not had another child because we are frightened that if we do, it will be taken away again and I cannot afford to lose another child” (PWLD 03).

This evidence highlighted that having their children taken into care against their wishes was a burning issue among PWLD. This is at a time when the prevalence rate of parents with learning disabilities seem to be rising and they appear to be over-represented in child protection services (McConnell, Llewellyn and Ferronato 2002; Booth, Booth and McConnell 2005). International studies show that between 30% and 60% more of parents with learning disabilities are likely to be a subject of care order application compared to parents in the general population (Booth and Booth 2004). This mirrors a study conducted in Australia which examined data of 77 parents with 116 children between them. The study found that 1/3 of the 116 children were taken into care (Bowden 1994). This is consistent with the findings of a national survey of 430,257 parents with intellectual disabilities in USA. The study found that of this total number, 219,357 of them (51%) still lived with their child and the rest (49%) no longer lived with their child. In the United Kingdom, a study by Emerson et al. (2005) concluded that 48% of parents with learning disabilities were not living with their children, who were assumed to have been taken away from them.

However, the Joint Committee on Human Rights (2008) pointed out that there is high potential for the removal of children from the care of parents who have learning disabilities which can be unjust and a violation of their right to family life. As reflected in this study, parents are often not told why their child is being taken away. The Joint Committee believes that prejudice and lack of understanding of these parents contribute to this problem. This is in line with the revelations that removals can still take place despite lack of evidence of maltreatment (Feldman 1998; McConnell and Llewellyn 2000). Hence, a significant number of decisions to take children away is based on the expectations and assumptions of professionals involved. This subjection to disapproving and critical attitudes from others means they are likely to be judged against stricter criteria than those of other non-learning disabled parents (Aunos, Feldman and Goupil 2008).

A consistent theme emerging from the respondents' narrative was that most parents lack professional help with parenting training before their children are taken into care. PWLD 02 suggests that removing children should not be the first intervention. More effort should be made to provide training to parents with learning disabilities before decisions to remove children can be taken:

- “A lot of social workers need to be aware about how they treat parents with learning disabilities. They should not always pick on things PWLD cannot do and not on what they can do. It will be helpful for them to come up with training programmes to help parents with learning disabilities rather than simply take away their children. I do not mean we are always good parents and I am not saying all social workers are bad apples. There are some who want things to work better. But for things to get better parents with learning disabilities will need training to look after their kids and not for their kids to be in the care of social workers and doctors”.

The consensus among scholars is that proper parenting support can lead to fewer children being taken away (IASSID 2008). A significant number (33%) of these parents have good enough parenting skills (Willerms et al. 2007). Yet, the suitable support is rarely available and what is available is rarely effective to help those seen as doubtful or assessed as not good enough parents (Glazemaker and Deboutte 2013). In another study, Tarleton and Ward (2005) found that parents were able to keep their children after receiving appropriate support and training. Similar findings were reported by Starke et al. (2007) on the initial implementation of an Australian-based programme for parents with learning disabilities. The consensus among the researchers is that effective support and training is one that is: build around the strength of parents, performance rather than knowledge based, focusing on the whole family rather than just the family or the child, shows greater understanding of the factors that can have adverse effects on parenting and effectively identifies issues specific to the individual parent (McGaw 2006; Mencap 2010).

Questions have to be asked about why parents with learning disabilities have continued to complain about inappropriate removal of their children. Various factors have been identified by different authors. For example, McGaw (2000) identified lack of positive attitudes and of evidence-based practice in this area. Gibbs et al. (2008) found that many services are not well equipped to respond to the needs of parents with learning disabilities. Many lack knowledge, preparedness and

experience in addressing issues surrounding the needs of parents with learning disabilities. Similar findings were reported by Alder et al. (2005) who reported that half of the optometrists in their study did not receive learning disabilities related training. As a result they lacked both knowledge and confidence in addressing the needs of PWLD. A recent study (MENCAP 2010) found that midwives had not received any training in learning disabilities, had difficulties identifying parents with learning disabilities and did not know where to access resources and specialist services to support parents with learning disabilities.

Lack of training among practitioners is central to this problem of inappropriate removal of children. It would seem these marginalising practices continue to be influenced by presumptions of incompetence of PWLD (McGaw 2006). Hence, the way forward should involve designing national and compulsory training programmes for practitioners working with parents with learning disabilities. Programmes should emphasise the integration of addressing the problem with sensitivity, respect for rights of both the child and parents, evidence-based practice and the clinical expertise in this area of intervention.

Summary:

This study confirms Young's view that the marginalised rely on and have their lives controlled by the very professionals and services which were meant to provide them protection. The dependence is strongly associated with lack of paid employment and lack of resources to improve their lives. This dependence also gives the professionals and services the power to control their lives. Many respondents voiced strongly against having their children taken away into care. For some of them, this is like an attack on who they are as a social group. It would seem that many practitioners lack confidence and knowledge of working with parents with learning disabilities due to not having received training specific to parents with learning disabilities. Hence, the study advocates for training of all professionals working with parents with learning disabilities for better understanding of issues involved to avoid oppressive removal of children from their parents with learning disabilities.

LACK OF SOCIAL RELATIONSHIPS AND RECOGNITION:

This study highlights that PWLD lack social relations and recognition by society providing a further illustration of how marginalisation can affect PWLD. This echoes Young's assumptions that

marginalisation also entails serious non-material deprivation including lack of social relationships and recognition of the marginalised social group. Respondents in this study indicated that most PWLD have social relationships with other PWLD, professionals who work with them in various institutional services and some family members. The few relationships outside PWLD, institutional services they receive and family, are mainly functional relationships with people such as shopkeepers, bus drivers and church leaders. Many have not been able to establish meaningful relationships even with their neighbours. For example, PWLD 06 pointed out that he was never accepted by his neighbour and ended up moving home:

- “I remember one of my neighbours, he was terrible. He just hated me and he never accepted me as his neighbour that I ended up moving to another flat”.

When asked about his social relationships, PWLD described them as “...other PWLD and members of staff who work with me”, the same who supported the accommodation service he was in. PWLD 02’s only friends outside the learning disabilities and institutional services were the shopkeepers near where he lived:

- “I have good friends, I get along with these people without learning disabilities who run the chip shop and I feel they respect me”.

Practitioner 01, perceived this lack of social relationships with the general population as a clear indication of not only non-acceptance but also as a subtle way of non-acknowledgment/recognition of the existence of PWLD. For her PWLD were physically “living in the community but still in their own institutional world”.

These experiences of little or no interactions with the general population have been reported by various studies. A significant number of these studies focused on evaluating the extent to which integration was successful among PWLD relocated from institutions. This included a comprehensive review of literature in New Zealand by Bray, Gates and Beasley (2003) which concluded that community presence did not guarantee increased community relationships. Their results showed that some community-based residential settings had no interaction with other people outside where they resided. Even where there was interaction it was only minimal, infrequent,

involved small groups of PWLD and did not take advantage of the potential for further interactions. The few social activities attended by PWLD were related to specialist services which were arranged by staff and family. This is in line with another study by Bigby (2008) which investigated changes in the nature of the informal relationships of residents 5 years after leaving an institution. Findings pointed out that some residents did not form new relationships after relocation and for others regular contact with a family member even decreased. A significant number comprising 62% of residents examined did not know any other person outside the service system who knew them well or monitored their well-being.

Some studies focused on investigating the structural and functional characteristics of social networks/relationships. Asselt-Goverts, Embregts and Hendriks (2013) reported that the number of people in each of the 33 PWLD respondents varied between 4 and 28. These were mainly family members (42.65%), acquaintances (32.84%) and professionals (24.51%). In a separate study of 213 PWLD, Forrester-Jones et al. (2006) observed that the average network size was 22 members. 43% of all participants' social network members were staff, 25% were other PWLD and only a third of the members were outside the LD services. Staff members were the main providers of both emotional and practical support followed by co-peers with learning disabilities.

Other studies compared levels of social relationships between PWLD and people with other disabilities (without learning disabilities). Lippold and Burns (2009) compared social networks among PWLD and other disabled people without learning disabilities. They found that PWLD had more restricted social networks than other disabled people despite being involved in more activities. Their social support was mainly from family and carers and a few with non-disabled people. But people with other disabilities had larger social networks and had a balance of support from both non-disabled and disabled people.

Whatever type of study, they all concur that PWLD experience significant social marginalisation. This lack of active interactions and formation of meaningful relationships in communities in which they reside have continued to persist despite the many years after deinstitutionalisation. However, the need for such social relationships cannot be underestimated. Simplican et al. (2015) highlighted that social networks or relationships and recognition are part of social acceptance and key to achieving community integration. According to Shpigelman and Gill (2014), they can enable

PWLD to establish and develop relationships with real-world friends just like any other member of the general population. For Devinat (2013), social relations can enhance employment prospects and access to shared resources. At individual level, they can help to instil confidence, sense of belonging and sense of safety (Bray, Gates and Beasley 2003). Hence, there is need to take notice of the calls of PWLD themselves for greater support to reduce social marginalisation (Duggan and Linehan 2013), and to establish the factors that can positively influence expansion of these informal social networks or relationships (Kamstra et al. 2014).

Section Conclusion:

In short, PWLD are a deeply marginalised social group. This is through processes that operate at a large scale to expel them out of work, diminish their ability to access resources, create severe material and non-material deprivation and impose their dependence on institutions and professionals. The complexity of these cycles of processes is such that it is difficult to separate them as natural causes and consequences of marginalisation as they are all tangled up together to form this mesh of processes that lower the social standing of a whole social group.

Contribution towards Young's notion of Marginalisation:

Section one confirms and adds to Young's (1990) notion of marginalisation as characterised by exclusion from paid work, lack of access of basic resources, dependence on institutions and lack of

social interactions and recognition. This section will challenge the original constituents of marginalisation identified by Young. Based on evidence from this study, it would seem that Young's emphasis on the employment element may have overlooked the fact that marginalisation can also occur in the early stages of people's lives and they do not have to wait until they get into adulthood before they are marginalised. Young's account did not go far enough to highlight and appreciate the substantial role education and family can play in marginalising social groups. Hence, this study will argue that negative experiences of family life and lack of credible education should also be considered as key elements of this form of oppression to provide a round picture of experiences of marginalisation disclosed by research respondents.

NEGATIVE EXPERIENCES OF FAMILY LIFE:

While the family is perceived as a major social institution that offers a broader kinship network upon which people can fall back for protection during difficult times, this may not always be the case with PWLD. The stories they shared in this study suggest that their marginalisation can start in the family itself. This can be in the form of being abandoned/disowned by parents. According to PWLD 02, abandonment can be in the form of negative perception of the child and then doing little to engage or accept the PWLD as a full member of the family:

- “My dad never liked me. I was his first born and I was not the ‘perfect child’ he expected. He never treated me the same as he did the other children - he sees me as someone from abroad. He told me I could never have a good job, never have kids of my own and I will never live on my own. And I have proved him wrong. I can forgive everybody else for treating me like this but not my own dad”.

This can also be in the form of the actual physical separation of PWLD from their families and placing them in care institutions as expressed in two statements below:

- “It is sad that there are many families who have disowned a family member with learning disabilities and left them at the mercy of health and social services. Many people in residential homes and hospitals (mental health) have not seen their families for a long time. They are only seen by services people such as advocates, befrienders, doctors and nurses. Where they are seen by their families, it may be just for three or four times in a year” (Practitioner 10).

- “There are other PWLD whose families have completely abandoned them and their parents are not known to the service or the person with LD themselves. They see the support workers and social workers as their close network. The residential home does everything for them including things like birthday celebrations, clothing etcetera because they have no one else in their lives” (Practitioner 09).

But respondents also recognised that there is a danger of demonising parents whose intention was never to cause harm to their children and whose life circumstances forced them to place their children in what they thought was in the best interest of these children. For example, Practitioner 09 understands that parents may send their children with learning disabilities into care because of two reasons: 1) They may find it difficult to come to terms with the disabilities of their children and 2) They may not be able to deal or cope with some of the behaviours that come with learning disabilities:

- “Some parents cannot cope seeing their disabled child on a daily basis. As a result they send them away to residential care like where I work. It is not because they hate their children but because they cannot cope. It is also a lot work to deal with some of the behaviours that come with autism and learning disabilities. So they send them into care where they can be looked after by people trained to look after PWLD”.

The families abandoning their own relative or child was a sensitive topic but one which respondents of this study felt was important to highlight in order to better understand their marginalisation. From this evidence, it is clear that families can have a marginalising and disempowering effect on their own child/relative with a learning disability. This reinforces the findings of Hutchins’ (2013) study. The author concluded that there is a statistically significant relationship between a child’s diagnosis of disability and, among other issues, abandonment of the child affected. This is mirrored in Dale-Harris’s (2013) report which revealed the thousands of disabled people neglected and abandoned in Romanian care centres. Disabilities International estimated a figure of 9,000 babies being abandoned to these centres by their families each year mainly due to having disabilities at birth.

Morganthau and Peraino’s (2000) report about affluent parents who abandoned their 10 year old son is supported by current evidence that inability to cope can lead families to place their relative with

disabilities in care or hospital. The parents drove their severely physically and intellectually disabled child to a hospital for children. They told staff that they wanted their son to be admitted. When the staff went to look for the doctor, the parents disappeared and were later arrested for abandonment. Here the issue was not money as the parents were well-off, but was a direct relationship between the disability of the child, inability to cope with care demands and the abandonment of the child.

LACK OF CREDIBLE EDUCATION:

Education is one of the essential resources that can equip people with the knowledge and skills they can use to improve their life chances and their socio-economic environments. The evidence from this study suggests that Young overlooked the marginalising effect this can have on an entire social group. Respondents were very clear that the institutional aspect of the schools they attended (SEN schools) and the poor quality of education they received in these schools were central to the many socio-economic difficulties they faced later in life. With such enormous impact on their lives and its strong association with their limited employment opportunities, this study argues that lack of credible education should be considered a separate key element of marginalisation in its own right.

The Institutional Aspect of SEN schools:

The general consensus among respondents was that SEN schools they attended were inherently segregatory institutions. Their understanding was that such schools were purposefully used to separate PWLD and those without learning disabilities from the early ages of their lives. For them such a separation in childhood marked an early start of their community or social exclusion and laid the foundation for further marginalisation in their lives. With such strong feelings against the segregation of PWLD in SEN schools, respondents were quite resolute in their voices that all children should complete their education in mainstream schools and that the SEN schools should be closed: This is reflected in these comments:

- “It was like we were separated from the rest of the population from when we were children. We never got the chance to know each other, they did not know us (non-learning disabled children) and we did not know them. This is the reason why when we mix with non-LD people we stand out (we are seen as different or abnormal). Then people treat us differently, laugh at us, call us names and hate us” (PWLD 02).

- “I know it is happening in Ireland. They put people with and without learning disabilities together in the same schools. They are going to try them in grammar schools. I know it is good because they are putting them together instead of splitting them apart. I think it should be like that” (PWLD 01).
- “If I was the government, I will shut down all the special schools and mix everyone in the main schools. This will be the best thing to do in order to change the attitude towards PWLD and it can be done” (PWLD 02).

It can be interpreted that the institutional aspect of these schools seems to be at the heart of the problems they face. This is marginalisation in the form of physical segregation away from mainstream schools, which comes with it a stigmatising label ‘Special Educational Needs’ schools (Giddens 2006). Runswick-Cole and Hodge (2009) believe this locates the problem in the children with learning disabilities. This can then generate negative images of these children and in turn shapes the types of policies formulated, the practice of education delivered and the educational experiences PWLD endure. Ultimately, the sense of detachment is produced which alienates such schools from society.

Whittaker (2001) has strongly condemned the existence of SEN schools arguing that inclusive education will not be implemented in a meaningful way when this system of special schooling and segregation is intact. According to the author, even where many can be supported in mainstream schools, the system creates new labels such as ‘complex, disorder, challenging’ which help to ensure that the actual number of PWLD found in SEN schools remains consistent. As reported by Heslop and Abbott (2009), this results in large numbers of children with learning disabilities being separated from local schools and excluded from local communities from early childhood. This is consistent with Northway’s (2006) argument that the notion of SEN schools is problematic as it emphasises on separateness, reinforces the perception of outside the mainstream and marginalises those who attend such schools.

This demonstrates that Youngs’s notion of marginalisation is limited as it fails to identify physical segregation as another form of marginalisation. The powerful voices of the respondents’ of this

study were resonate in that this form of marginalisation cannot be ignored as it places them at serious disadvantage with long term impact to their lives like any other form of marginalisation.

Poor Quality of Education:

The general agreement among the study respondents was that the poor quality of education they received in SEN schools was a fundamental mechanism of their marginalisation. In their narratives they described the education they received as of poor quality, one that was not worthwhile and one that never prepared them to face realities of the world:

- “I did not do much there and it was just a waste of time. I was angry about it, quite bitter.... I felt that the school was not teaching me the right things. It never prepared me for the world of work. So when I left school I found the world very scary” (PWLD 03).
- “I am 27 years old, I went to school but ended it because I was not good at school... ..I cannot read and write and have to ask other people to read and write for me” (PWLD 05).
- “In my opinion it will just be a formality of saying PWLD are going to college or school... no one really looks at how well they are doing and whether they are going to achieve something or use that knowledge they acquire somewhere else... Their support workers will do all the cooking and they are told ‘no you cannot use the stove because you may burn yourself’ and yet they have completed a cooking course at college” (Practitioner 04).

In agreement with Runswick-Cole and Hodge (2009), it would seem that the respondents’ argument is that as long as this SEN school system is in place, not much will change for PWLD in terms of the quality of education they receive and the maintenance of their marginalised position. According to the authors, the several changes introduced over many years by different governments have not produced the high quality and relevant form of education PWLD are calling for. The lack of relevant resources that enable the existence of systematic acceptable standards of teaching PWLD outside SEN schools has continued to prevail (Watson 2009). This was reflected in a recent review of policy on SEN schools by Ofsted (2010) which reported widespread weaknesses in the quality of education in SEN schools. The review highlighted that policy on SEN schools is already so heavily saturated with legislation and guidance that further additions to policy and guidance have rarely

introduced any noticeable changes. Instead, the system has only become or remained complex for all stakeholders involved including teachers, parents and the pupils with learning disabilities themselves.

The views of PWLD in this study reinforce Whittaker's (2001) idea that catering for differences in educational needs of PWLD is not through more guidance and policies that strengthen or simplify SEN schools. Whittaker argues that SEN schools have already demonstrated they cannot guarantee PWLD with the appropriate resources and support they need to meet their educational needs. The existence of this separate system has only helped to maintain the provision of a second class provision of education compared to mainstream schooling. "Appropriate support to access schooling should not be seen as 'conditional' or as an 'optional extra' or dependent on 'good will' or for 'expert delivery only'. Supports should be so effective and available that they are not seen or presented as 'special'" (Whittaker 2001:13-14). From this standpoint, Whittaker (2001) too advocates for the closure of SEN schools. The author argues that if appropriate levels of support and resources go into mainstream schooling the need for SEN schools will diminish.

However, others believe that the problem is not simply in SEN schools per se, but is largely located in the notion of 'special educational' schooling. This has been seen as the source of the poor quality of education in any school PWLD attend (whether SEN schools or mainstream schools). This is reflected in the study by Webster and Blatchford (2013) in which they made some class observations across 45 mainstream schools. The authors observed that even in mainstream schools the quality of education for PWLD is poor. Qualified teachers rarely had high level involvement in planning and teaching pupils with educational statements such as PWLD. Generally, the least qualified staff were assigned as the primary educators for these pupils in most need of the relevant expert skills and knowledge qualified teachers ought to possess. As a result of this, many of the affected tended to make less progress than the peers without statements. This corresponds with a more recent study by Bajwa-Patel and Devecchi (2014) who reported that there remains little choice of suitable provision of PWLD schooling. In their conclusion 'nowhere seems to fit' as either they had to compromise the academic or the social aspects of their children's education. This is despite a plethora of policies and laws to aid parents to choose a school in the best interest of their child with learning disabilities.

This study adds the voice of PWLD to this debate of how best to improve the quality of education they receive. Their powerful views cannot simply be dismissed and the need to understand the education problems and potential solutions of these problems from the perspective of PWLD themselves cannot be overlooked.

Consequences of Lack of Credible Education:

Respondents in this study pointed out that the lack of credible education has resulted in: many PWLD leaving secondary education without the relevant skills and knowledge to further education and to access the competitive open labour market; and marking their marginalisation in the early ages of their lives predisposing them to a wide array of forms of marginalisation.

PWLD 01 expressed his difficulties and frustration of leaving secondary education without any qualifications then struggling to get a job or find other means of self-reliance:

- “I did not go to these big Universities. They wanted me to pass this and to pass that before I could get into one, I felt awful. People told me you haven’t got GSCE, you haven’t got this qualification, you haven’t got that other pass and it makes you feel you are not there in any way... If a person with learning disabilities wants to have a job, which many other people are applying for too, they will ask you to come for an interview and they start asking you questions: Right then sir: What qualifications relevant to the job have you got? My answer will be I have got none. And they will ask me: So what makes you think that you can do this job then? I cannot give a good answer because I do not have what is needed to get that job”.

This echoes Practitioner 02’s understanding that:

- “many PWLD do not have the skills and knowledge to be employed in high paying professions”.

These respondents’ narratives are well documented in government reports and in the literature. The Government’s White Paper Valuing People is clear that many PWLD complete their secondary education without any qualifications. As a result they are not likely to continue into higher education and/or get into paid employment (DH 2001). A recent literature review by the European Agency for Development in Special Needs Education (EADSNE 2012) showed that this problem is

widespread across other European countries. The review reiterated the fact that people with special educational needs attain the lowest levels of education and that their access to vocational and professional training is severely restricted.

Reinforcing this view, Beyer and Robinson (2009) suggested that it is not coincidence that many PWLD are unemployed. The various factors that increase their likelihood of employment such as having an academic qualification, receiving vocational training and integration with non-disabled peers are not in their favour. For many PWLD, this direct relationship between education, skills training and employment is broken due to the lack of strong compulsory educational programmes that link well with vocational or professional programmes (EADSNE 2012). While this is the case, Sitlington and Clark (2001) suggest that much of the research has focused on transition processes and future employment with little or no attention given to the actual training processes that help to equip PWLD with the necessary job market skills. Until these links are connected, many PWLD will continue to experience a life-long cycle of marginalisation.

Summary:

Although lack of employment and material deprivation are essential forces of marginalisation, this study shows that the marginalisation of PWLD can go beyond income matters. As children, some are from affluent families and yet they can still be abandoned in care institutions and relegated to segregated schools. The negative family life experiences and lack of credible education become key elements that aid to mark the commencement of marginalisation among PWLD in childhood. These will not only link closely with other elements of marginalisation but also predispose PWLD to other forms of oppression both in childhood and adulthood. Importantly, the marginalisation experiences disclosed by PWLD in this study would not be complete without these additions done to the elements of marginalisation suggested by Young (1990).

Overall Conclusions:

The evidence from this study confirms and adds to Young's framework on oppression. PWLD's experiences reported by respondents resonated well with the framework's definition of marginalisation characterised by: 1) Exclusion from paid employment; 2) Lack of basic resources; 3) Severe deprivation; 4) Dependence and lack of autonomy; and 5) Lack of social relationships and recognition. However, Young seems to have overlooked some subtle differences between social and

economic marginalisation. For a significant number of PWLD in voluntary work, exclusion from paid employment did not always translate into social marginalisation as they were able to engage in social activities. Fundamentally, Young failed to notice the substantial role education and family can play in marginalising social groups such as PWLD. They are key elements of marginalising forces that provide that link between oppression in childhood and adulthood. It is because of this important link that it can be argued that the various marginalising experiences affecting PWLD are not ad hoc or isolated events. They are on-going, usually life-long, which commences from childhood and progress into adulthood. This can be explained as a continuum of oppression from childhood and progressing into adulthood. PWLD spoke of their segregation in SEN schools in childhood, the poor education they received and how this translates into lack of life opportunities, stigmatised identity and poor quality of life. Within the continuum will be a complex web of processes that interact and reinforce each other to maintain a cycle of their marginalisation. An understanding of these marginalising processes should help policy makers, scholars and practitioners to find possible solutions to address the social difficulties PWLD face.

CHAPTER 2: VICTIMISATION AS A FORM OF OPPRESSION

INTRODUCTION

This chapter will use the research findings of this study to suggest a new way of understanding oppression. The findings will be interpreted in support of reclassifying Young's notions of cultural imperialism, exploitation, violence and powerlessness into a more integrated collective experience of oppression which can be labelled as: Victimisation. The different concepts of oppression expressed by Young produce a complex interlink and the experiences of PWLD do not always fall neatly into such neat categories. For example, it is not straightforward where to place some fundamental experiences of discrimination such as members of the public avoiding community facilities used by PWLD. Other experiences can fall into more than one category leading to repetitiveness in explaining the same form of victimisation in different categories of oppression. This is the case with issues such as mate crime which can involve exploitation, violence and powerlessness. Furthermore, based on the evidence from this study, the psychological, mental health and social consequences are part of these oppressive experiences which become not only the means through which PWLD are further restricted, but also the means through which they can contribute to their own oppression. Hence, subsuming cultural imperialism, exploitation, violence and powerlessness into one broader form of oppression: Victimisation, which can accurately represent the various forms of oppression other than marginalisation disclosed by respondents of this study.

Victimisation can be defined as a process or mechanism in which individuals, social groups and communities become targets of harmful actions or omissions at the hands of other human beings (Keitsman 2009; Kostic 2010; Beadle-Brown et al. 2013). According to Dussich (2006:118) this harm should be profound enough to cause "a violation of rights and/or significant disruption of their well-being". This encompasses a range of behaviours from minor acts such as staring, laughing and name calling (Beadle-Brown et al. 2013), to major forms of harmful conduct such as significant damage to property, persistent bullying and harassment, serious physical assaults, widespread negative attitudes and in rare cases, murder (MENCAP 1999; Disability Now 2013).

Hence, in line with Young's idea of expressing people's oppression based on how they experience it themselves, the victimisation experiences of PWLD in this study were characterised by: 1)

Widespread negative attitudes: This will highlight the extent of and the factors involved in sustaining negative attitudes towards PWLD; 2) Systematic acts of targeted violence: The nature and pervasive characteristic of violence against PWLD will be discussed in this section; 3) Systematic abuse: This will focus on institutional abuse of PWLD by professionals and mate crime as a form of exploitation by members of the public; 4) Secondary victimisation: Here further victimisation experienced following original victimisation is seen as playing an important role in oppressing PWLD; 5) Severe psychological/mental health consequences: This section will discuss how the consequences of victimisation often culminate in serious mental health problems which in turn can exacerbate their situation; and 6) Reaction to victimisation: This will highlight that PWLD learn to tolerate and live with their victimisation which may be seen as a key strategy to deal with their experiences.

WIDESPREAD NEGATIVE ATTITUDES TOWARDS PWLD:

Attitudes are a complex collection of feelings, beliefs, values and disposition which characterise the way we think or feel about certain people (Scope 2014). The problem of widespread societal negative attitudes was a theme reiterated throughout this study. The general agreement among respondents of this study is that PWLD remain subjected to stereotypical portrayals that hinder their integration into mainstream society. Key to these attitudes is how learning disabilities is interpreted in ways that create images that represent PWLD as: people who require pity or care, burden to society, not capable or useless people, objects of ridicule, unpredictable and a threat to members of the public so that they should be separated from the rest of the society:

- “They do not think PWLD are capable of doing anything and they are not given a chance to prove what they are able to do” (PWLD 01).
- “Difference is a big issue here and the society’s reaction to this difference is to view a person with learning disability as less able and a person who needs to be cared for or looked after” (Practitioner 07).
- “There are members of the public who think that PWLD do not deserve to live in the community and need to be in care institutions. For example, a lady near where I live, she thinks all people with learning disabilities are bad people and should be in an institution under 24 hour care. But we are all different (PWLD 11).

These findings resonate well with current literature on attitudes towards PWLD and the disabled people in general. For instance, Ritchie (1999) points out that the problem of negative attitudes towards PWLD is an area that requires attention as PWLD often identify societal negative attitudes as the most potent and detrimental stressor in their lives. The author argues that these negative attitudes have remained firmly embedded or institutionalised in society and act as the forces that maintain the historic disadvantages PWLD have continued to face. This is consistent with a longitudinal study (Staniland 2009) which measured changes in attitude towards disabled people between 2005 and 2009. The study indicated that negative attitudes and level of prejudice against disabled people remained strong over the years. These attitudes were worse towards PWLD as members of the public revealed that they were more comfortable interacting with people with physical and sensory disabilities compared to PWLD. More than half of them were not comfortable with PWLD holding a position of authority such as a Member of Parliament. A recent mixed study (OPM and Ipsos Mori 2014) asked the disabled people themselves about whose attitude they would most like to see change in. The results showed that 29% wanted to see a change in the general public attitudes, 23% wanted change in local authorities and government staff, 23% in health and social care professionals, 15% in other professionals, 10% in public transport staff, another 10% in family members and 8% wanted to see change in attitude towards their friends without disabilities. These findings indicate not only widespread negative attitudes towards disabled people but also highlight the need for change in these attitudes across society.

Questions have been asked about why these strong negative attitudes have persisted despite deinstitutionalisation and policy on community integration, 20 years since the passing of the Disability Act (1995). For example, in this current study, PWLD 03 wants to know why society has maintained these negative attitudes and is finding it hard to accept PWLD. Comparing the experiences of PWLD and black people he stated:

- “My conclusion is that people’s attitude is not good and they have to stop this bad attitude and start treating PWLD like human beings. In the past whites and blacks did not sit next to each other on the bus, but now they do. Today, why is it proving difficult accepting PWLD?”

The general consensus among authors is that the sources of these negative attitudes remain the same and not much has been done to address the problem. Konttinen (2006) identifies the emphasis on

care of PWLD as a major source of prejudicial attitudes towards them. The author points out that this emphasis has meant that policy towards PWLD is largely care or service-led and the call for improving their lives has remained within the confines of services. This reinforces society's perception that PWLD cannot lead ordinary lives (life outside care services) and society's expectation that PWLD take or accept a life-long sick role. According to Parson's (1951) sick role model, the sick person is not responsible for their illness, has the right to be taken care of and should be exempted from normal societal responsibilities and obligations. This becomes a social mechanism through which the lives of PWLD has been continuously shaped (Varul 2010).

More closely related to this emphasis in care is the point raised by Ramcharan and Borland (1997), that efforts to change attitudes have continued to be directed towards professionals working with PWLD and not to the wider members of the public. Yet, according to Ritchie (1999), these public attitudes are essential as they influence the way policies are interpreted and enforced. Hence, interventions outside care services targeted at changing directly the negative attitudes of the wider society may prove to be the fundamental approach needed to improve the way PWLD are perceived (Dowson 1997; Konttinen 2006).

Adding to the debate, Livneh (1982) believed that the historical emphasis on personal productiveness has been another key factor in maintaining these negative attitudes. The author pointed out that PWLD remain judged in terms of social and economic competitiveness. Although progress has been made with social enterprises and supported employment schemes, gaining full-time paid employment remains a challenge for most PWLD (Beyers et al. 2010). There are still many in society who believe PWLD cannot work (Humber 2013) and as expressed by respondents, the result is they continue to be seen as abnormal people, less capable, not able to contribute to society and people who cannot provide for themselves and their dependents. With little emphasis on how society can re-organise the workplace to accommodate their needs and how best to invest more in getting PWLD in paid employment, these views are likely to persist and will be a long time before society changes the way it treats them.

The general agreement is that the approaches used in the past have helped, but on their own they are not adequate. For example the efforts to change attitudes through use of new concepts and replacing unpleasant labels with more acceptable ones has not gone far enough. The new labels such as

learning disabilities and intellectual disabilities have maintained the stigmatising and oppressive connotations from the replaced labels such as idiot, imbeciles and mental handicap (Galvin 2003; Schalock et al. 2007). Thus, this calls for new strategies to deal with transforming society's attitudes that build on the positive progress achieved, learn from the mistakes of the past and which are evidence-based.

It is clear that the issue of negative attitudes matters due to the fact that they translate into behaviours towards PWLD which play a key role in contributing to their victimisation. The combination of highlighted factors involved in explaining society's negative attitudes and their oppressive behaviours indicate how complex an issue it is to address. A mix of interventions is necessary such as changing labels, some progress in supporting PWLD into work and living in the community. It would seem these interventions have been generally focused to a small proportion of society, mainly those working with PWLD, and failed to target members of the public directly. Hence, this study argues that fundamental changes may occur if awareness interventions are felt across all government sectors, by all practitioners outside learning disabilities settings and directly targeting members of the public.

Systematic acts of targeted violence against PWLD:

The widespread negative attitudes have been associated with the significant risk and systematic acts of targeted violence against PWLD living in the community. Respondents in this study reported a wide range of forms of violence against them which they defined as characterised by high levels of bullying and harassment. These included:

Being verbally abused (ridiculed and called names):

- “They used to pick on me calling me these horrible names such as spastic, idiot and nutter, which were not very nice” (PWLD 10).
- “I was usually called backward and worse names which I am not comfortable to tell you” (PWLD 11).

- “A staff member and wheelchair bound PWLD were in a restaurant having a meal. Someone came in and asked the question: What are they doing here as they referred to the PWLD” (Practitioner 01).

Being forced out of public buildings:

- “In the night club, my dad went to the toilet. He took a long time there and I was getting worried. So, I went to the reception area to talk with the receptionist about my dad who had taken that long in the toilet. What I got from the receptionist was abuse and swearing. I said excuse me don’t talk to me like that and I was starting to get upset. Next thing I noticed – I was put down on the floor by security guards. I was pulled outside face flat on the floor. I had not done anything wrong. The police were called, I was arrested and taken to prison. When it was checked on the CCTV, it was observed that I did not do anything wrong to the receptionist, instead it was the other way round and she was the one who actually verbally abused me. But I was in the police cell for 13/14hrs” (PWLD 10).

Being physically assaulted:

- “It was one verbal abuse to another verbal abuse and then it got to physical abuse - throwing shoes at me and hitting me (PWLD 02).
- “At one point they became really horrible and tried to light my hair and they told me it was a joke to try lighting my hair with a lighter. Worse things happened, they carried on...” (PWLD 10).

Having their properties attacked:

- “I have seen a person (with LD) who was living in a flat. She had a daughter. On a daily basis and every night she was scared to death. Her lights had to go off early before 19:00hrs and used to then find somewhere safe to hide in her own flat. She did not feel safe when they ganged up around her house at night. They will start by shouting names and then will end up chucking stuff down the windows and smashing her windows” (PWLD 01).

- “I had just moved to this flat after experiencing a lot of hate crime where I lived before. It was okay at first but suddenly they started at it again, throwing bricks and various objects at my flat. These were young lads and their attitude was not right” (PWLD 06).

In the individual interviews respondents described these forms of unprovoked violence as the inevitable which has become part of their lives. They can only try to find the best ways of living or coping with it. Verbal abuse was the most common form of violence mentioned by all respondents. In some cases the verbal abuse can be followed by physical assaults such as pushing, pulling hair, punching, kicking and being hit by objects thrown at them. Some incidents can be one-off but others can become complex as in the cases of respondents who reported being bullied and harassed more frequently and experiencing more than one form of bullying and/or harassment over prolonged periods of time. These findings support the results of one of the most comprehensive studies (Mencap 1999, 2008), which suggested that bullying and harassment were the most common forms of violent acts against PWLD institutionalised across society. Similar findings were reiterated by the Equality and Human Rights Commission (2009) in their study of disabled people's experiences of targeted violence. They suggested that the prevalence of these acts may be higher considering that on-going and low-level incidents may go undetected. Being specific about the types of violence against PWLD, a recent study (Gravell 2012) revealed that 27% of participants reported name calling, 23% reported attacks on property and burglary and 18% reported physical assaults and threats. In another study (Lerpiniere and Stalker 2008) participants recounted personal experiences of being told to leave pubs after one drink or not being served at all. A more recent study (Beadle- Brown et al. 2013) reinforced the complexity of these experiences with some of their research participants revealing repeated incidents of bullying and harassment for weeks, months or even years.

Respondents described these incidents of violence as happening everywhere they spend time: in their own homes; in public places (restaurants, street); public transport; employment institutions; within social care systems; social systems (housing) and social institutions (schools, family). This correspondences well with their assertion that the perpetrators can involve any member of society including children and the elderly; males and females, strangers and familiar people who they come across in these places or spaces they spend time. The finding that violence among PWLD can occur anywhere is well confirmed in studies by Mencap (1999), Equality and Human Rights Commission

(2009) and Beadle-Brown et al. (2013). A more recent study by the Foundation for People with Learning Disabilities (FPLD) in partnership with Lemos and Crane (2014) supports the evidence that perpetrators of violence against PWLD can be anyone including neighbours and children.

This is evidence to suggest that violence against PWLD is pervasive in society and that their experiences of violence cannot be limited to specific places or to a specific perpetrator. It is clear from the research evidence that there is a collective action of individuals, groups, social institutions and social systems and that violence against PWLD cannot be defined in terms of one or two unfortunate events that occur accidentally (Mencap 1999). These widespread acts of violence can be the indicators of how the legacy of institutionalisation has continued to persist in society and how PWLD have not been accepted in their communities (Wamsley 2005; Beadle-Brown, Mansell and Kozma 2007). As highlighted by the Equality and Human Rights Commission (EHRC 2011), this can also be an indicator of the lack of a systematic strategy to deal with this huge problem facing an entire social group. In their publication 'Hidden in Plain Sight', the EHRC reported systematic failures to prevent and tackle disability harassment across agencies which were meant to protect those at risk of harm. For them, this shows the deeper social problem society has with PWLD associated with the core underlying issue of widespread negative attitudes that engenders power to some members of society to act violently and abuse PWLD (to be discussed in next section). This seamless connection between these factors of oppression is evidence that reinforces the notion of victimisation which differentiates it from Young's fragmented framework.

Systematic Abuse [institutional and mate crime (exploitation)]:

Abuse can be defined as the misuse of power and control that one person has over another. Here intent is not the issue, hence, the definition is based on whether actual harm has been caused and on the consequences the harm has to the individual affected. This can occur in PWLD's homes, residential settings, supported living accommodation, educational establishments, clinics and hospitals (SCIE 2013). In this current study respondents have highlighted two main forms of abuse affecting PWLD: A) Institutional abuse and B) Exploitation.

Institutional Abuse:

According to SCIE (2013) institutional abuse is the mistreatment or neglect of people at risk which occur when the routines, systems and regimes of an organisation result in inadequate standards and

practice of care. It can also occur when organisations fail to act upon issues of poor standards or practice brought to its attention. In this study, respondents identified the following as some of the important forms of institutional abuse PWLD experience:

Physical and Sexual abuse

- “We all noticed that this male staff was a bit close to the female patient with learning disability. He will provide personal care to her on his own. He will take this female patient out on a regular basis. At times he will cuddle, rub her back and rub her hair. We questioned these behaviours and we suspected something worse could be happening so we reported. When this was investigated, it was found out that behind closed doors, he used to have oral sex with the patient. When he went out for a bike ride with the patient, he used to take her to the bushes where he sexually abused her. This had been happening over a long period of time. This girl in her 20s, had a diagnosis of psychosis and personality disorder. She was not in control of anything and probably thought that this man loved her” (Practitioner 02).

Neglect and Poor care:

- “One who comes into my mind is a lady with learning disabilities who was not well. The professionals took their time to insert a new feed peg and find her a new wheel chair. By the time this was done, she had started to lose her swallowing reflex, something which upset me” (Practitioner 01).
- “I started to identify the more subtle discrimination which can be institutional. For example, my experience of a GP who refused a person with learning disabilities a particular medication because it was too expensive” (Practitioner 01).
- A member of staff refused to take service user to the shops because he (staff) wanted to watch football” (Practitioner 09).

Financial abuse:

- “A support worker who enjoyed going out with service users in the community. Before going out, he would take out money from the service users purses (with their permission). When at the pub or café he would buy cheap and at times unhealthy food for the service

users and instead buy himself expensive food using service users' money. On return to the ward he will always write the wrong balances that there is always a shortfall in service users' monies" (Practitioner 10).

- "... the member of staff used to bring bits of paper using my money without me agreeing to it. When I got angry, I went to see a senior person within the organisation who said she needs to be investigated. She left the company before she was investigated" (PWLD 08).

Reports of these institutional abuses of PWLD have been documented widely in literature. For many years social and care institutions have been rocked by one scandal of abuse after another. The Commission for Health Audit and Inspection (2007) identified systematic abuse across one of the remaining largest long-stay hospitals at the time. The commission reported severe shortage of staff leading to a state of poor care and neglect of patients, serious incidents of physical and sexual abuse of service users by staff, lack of privacy and dignity for patients, and lack of policy on restrictive physical restraint and interventions. This was after a damning report into abuse in Cornwall where PWLD are reported to have suffered a catalogue of abuse and poor practice. Many service users with learning disabilities had lived in the hospital for many years with no plans to move them out of such environments. The abuse identified ranged from service users being given cold showers, having their food withheld, being tied to wheelchairs or beds and being inappropriately given medication to control their behaviours. More recently, an undercover BBC Panorama Documentary revealed some of the most shocking institutional abuses of PWLD at Winterbourne View Hospital in Bristol. The documentary showed service users being physically restrained inappropriately, physically assaulted and taunted. One service user was left outside in very cold temperatures, another was given a cold punishment shower and there were several incidents of hair pulling and forcing medication into service users' mouths. Senior managers and the CQC had failed to respond to early warnings of abuse raised by a senior nurse (BBC One 2011). Without this documentary these abuses might be continuing today.

Here the issue is not just about the high levels of abuse in institutions, but also about the continuity of these abuses over many decades. Questions will have to be asked about why we do not learn from these past and recent scandals. Jenkins and Northway (2012) looked into previous events of institutional abuse warning that institutional abuse will continue unless it is dealt with effectively

wherever it occurs. The authors pointed out that the same issues have been exposed in one investigated scandal after another stretching over many years. They observed that poor management, negative attitudes and poor competence of staff, poor living and isolated environments and powerless service users being left at the mercy of care institutions that control their lives are some of the factors common in scandals of abuse of PWLD. They also noted that the recommendations made in official inquiries of scandals are partially implemented or completely ignored. Then, we have a cycle of similar scandals and the subsequent cycle of enquiries producing similar reactionary sets of policy proposals.

While a lot of work has been put into attempts to safeguard PWLD, it would seem that profound changes are still needed to stop or reduce the existing levels of institutional abuse as well as to establish preventative measures that help to avoid further inhumane treatment of people on this current scale. As stated by Practitioner 10 in this current study and in the DH (2012) document: Transforming Care, senior managers of organisations and the relevant different agencies involved should be held to account for allowing to flourish a culture of abuse which sacrifice service users' safety for organisational needs and profit (EHRC 2007). Otherwise, the commitment required to ensure that the abuses are dealt with effectively will continue to be lacking. In addition, there may be a serious need to change the inspection approaches to ensure that inspectors are able to pick up signs of different kinds of abuse on their visits (Care Quality Commission 2014). Approaches should require inspectors to be based at the institution of inspection over prolonged periods of time to observe care given and to talk to both staff and service users. It should also be made easier for service users to report directly to agencies outside the organisation that provide care. Reporting routes are through a chain up to the management hierarchy. One missing link can prevent reports reaching the police. Much of the institutional abuse is not dealt with through legal criminal processes but rather through administrative routes such as formal complaints to services, staff dismissal and closure of institutions (Williams 1995). Cambridge (1999) was seen as invisible, warning signs and signals were ignored, and efforts were made to deal with the abuses internally to avoid wider political impact. Adequate resources and standards of care must be upheld to avoid what McDonnell et al. (2014) described as the "slippery slope" to abuse through recognition and prevention of development of cultures of abuse at early stages.

Mate Crime (Exploitation):

Mate crime is a form of victimisation in which PWLD are befriended by someone who takes advantage of the relationship to exploit or abuse them (Beadle-Brown et al. 2013). According to Thomas (2011), these relationships are established with the intent to cause harm and this can involve acts of humiliation, exploitation, cruelty and servitude (Thomas 2011). According to the Association for Real Change (2013), mate crime is an increasing invisible crime which can be difficult to identify. In this current study, respondents gave several examples of their experiences of mate crime or exploitation as highlighted in the extracts below.

- “Most of my victimisation comes from women. It is because when I have been trying to get into relationships they abuse me for my money, for accommodation and just to play with my feelings. Because I end in relationship with these women, they usually abuse me for money asking me to get them some money, lend them some money or buying them expensive things and so on. Some of them went behind my back to use my card and once they have enough money they leave” (PWLD 11).
- “I know of one person with learning disabilities who used to have a friend. That friend he met was a drug dealer. He (the friend) was using him (PWLD) to carry drugs for him- which was terrible. ... and it all escalated into something bigger like being asked to get involved in drug dealings. He was soon being threatened by various people and he got attacked one night because of his friendship with this drug dealer. That is how we got to find out what was going on.... When we did a room search we found large quantities of drugs in his room which he got through his association with his friend” (Practitioner 11).
- “Perpetrators look for vulnerable people: people who cannot communicate very well, who can be easily led or people who haven’t got many friends or family who live on their own, people who do not have the intelligence about who to contact, where to go and what to do in the event of being victimised or people who do not even notice that they have been victimised - many PWLD fall into these categories” (Practitioner 07).

Respondents spoke of PWLD being exploited for their benefits money, food and for their homes which can be used for free accommodation and storage of illegal drugs. It is because of the nature of this crime that many PWLD will not be aware that they are being exploited. The ‘mate’ can be a stranger who grooms the victim, friend, family member and practitioners. As pointed out by

Practitioner 07 above, the victim with learning disabilities is targeted because he/she has the characteristics that help to facilitate their own exploitation such as: being easily led, no friends and live on their own, not able to spot their own exploitation and unlikely to report their abuse or exploitation.

These findings reinforce the results of several other studies which have confirmed the existence of mate crime. The agreement between authors is that PWLD are at increased risk of mate crime and awareness of this kind of victimisation is important. A research project by Safety Net (2011) found that PWLD were being exploited to store stolen goods in their flats, led into drug dealing and forced into prostitution. These are criminal acts that can bring them into contact with the criminal justice system. A recent study (Beadle-Brown et al. 2013) reported the experiences of PWLD of being befriended by people who took their money and occupied their homes.

The case of Kevin Davies demonstrates the harsh realities of mate crime. He was treated like a prisoner by a couple and an acquaintance who had befriended him. They locked him in a shed without enough food to eat. They took his benefits money and beat him (Callanan 2010). More harrowing was the case of Steven Hoskins who was exploited and humiliated for over a year in St Austell in Cornwall. The gang who befriended him burnt him with cigarettes, took his money, forced him to walk around with his own dog's collar and lead and forced him to take 70 painkillers. They took him to the viaduct and forced him to hang by the railings as one of the gang members stamped on his hands until he fell about 100ft to his death. Gemma Hater was another victim of a brutal mate crime. At the age of 27 years, she was murdered by a group of so called 'friends'. She lived alone receiving a floating support to help her maintain her tenancy and to lead a more independent life. With no access to effective safeguarding support, she was targeted by a group of people who took advantage of her chaotic lifestyle and vulnerability to exploitation leading to her murder.

Although the notion of mate crime is relatively new, it remains under-recognised and is lacking academic base and definition, it is increasingly gaining professional and media attention (Roderick 2014). The few studies and in particular the high profile cases stated above show that mate crime is reality which cannot be ignored and needs to be added to the long list of the various forms of victimisation PWLD experience (Thomas 2011). Roderick (2014) emphasises the point that mate

crime is significantly distinct from manifestations of hate crime and abuse, hence, needs to be treated differently. An understanding of its manifestation should help prevent PWLD from going through the same harrowing experiences. The case reviews of the murder of Stephen Hoskins and others has shown that a better understanding of what was happening could have helped with earlier identification and interventions. In turn, this could have prevented the unnecessary prolonged suffering and the eventual death of the victims with learning disabilities. With the emphasis on community care and many PWLD living in the community, cases of mate crime are only likely to increase (Hamilton and Trickett 2015). Hence, more resources and research studies are needed in this area (Spink and Steward 2011). A clear definition may be required which identifies where exactly in this framework of oppression this notion of mate crime will fit in (Hamilton and Trickett 2015).

Secondary victimisation:

Secondary victimisation is additional traumatisation of victims due to responses they receive from others following the original victimisation (Okan 2011). The evidence from this study highlights that secondary victimisation has an important role in oppressing PWLD. It would seem that it does not only add to the immediate further traumatisation of the victims but also acts as a major barrier to gaining effective services from the criminal justice system. Below are some extracts showing views of the respondents of this study.

- “On our Hotline, some PWLD call us because they have already been through the official channels: they have spoken to the police, social services, they have gone through the advocacy groups; and that they are incredibly frustrated by the treatment they experience, not by the actual victimisation but the victimisation by the system. Because of that there has not been any resolution to their problem; I do not think there is confidence in the police’s ability to understand PWLD, not only in terms of communication but also in terms of empathy” (Practitioner 07).
- “When I got robbed, I did not feel I knew how to report to the police, so my mother went with me to report to the police. I thought the police were quite patronising. I thought they were talking to me as if I was the criminal. I felt really down and this got my mother upset. She told them there is no need to speak to my son like that, he has done nothing wrong. It is

because of that I will never go back to the police again. I will need a lot to convince me that they have changed” (PWLD 02).

Some evidence from the interviews suggests that the consequences can be more implicit such as the further traumatisation of victims due to responses they receive from others following the original victimisation. Both respondents with learning disabilities and practitioners highlighted that apart from having to cope with the pain of their victimisation, PWLD may also have to deal with the insensitive manner in which different services respond to their primary victimisation. This could be in the form of being stereotyped as people who are prone to lie and likely to be the victimisers themselves. As a result their stories are doubted and not believed. PWLD 02 expressed his disappointment and anger at the way he was treated by the police after he was robbed. He was left feeling blamed and perceived as the criminal himself and now would prefer not to report to the police again because of this experience.

Similar findings have been widely reported in the literature. A study (Keilty and Connelly 2010) in Australia interviewed police officers and sexual assault workers in order to identify the barriers affecting women with learning disabilities in successfully making statements to police following sexual assault. The study found that the police had maintained the same stereotyped attitudes and views of PWLD as the general population. They did not believe or take them seriously. Often, the women will be perceived as promiscuous and unreliable witnesses and assumptions will be made that the evidence they provide is already contaminated. The study also found that there was a confusion about what constitutes learning disabilities and how to respond appropriately to women with learning disabilities. As a result the procedures were not adequately followed, the necessary support was not sought and the relevant adjustments to the interview were not done. Similarly, HMIC and HMI probation (2013) and Sin (2013) have reported how people with disabilities prefer not to report their victimisation to the police as they fear they may not be believed or taken seriously. Both authors highlight the lack of confidence in the police force in communicating with people with learning disabilities and their reluctance in pursuing cases that rely on statements or witness testimonies of PWLD.

The evidence from this study’s findings and from the literature show how secondary victimisation, in particular by the police, can provide some insight into why many PWLD do not report directly to

the police and why the few complaints of victimisation are not successful. It has become one of the major obstacles in PWLD accessing the police and having a successful statement completed. Yet, these are key first steps towards prosecution of perpetrators and achieving justice for the many victims with learning disabilities (Keilty and Connelly 2013). This demonstrates the need for establishing greater awareness among the police force and training that can improve their understanding as well as the way they work with victims with learning disabilities. This should involve having access and working in partnership with other agencies for advice and support so as to ensure that: 1) The police themselves develop the required skills in communicating with PWLD; 2) PWLD have the confidence in reporting directly to the police; 3) PWLD have an equal chance to have a statement successfully taken; and 3) That the victimisation statistics involving PWLD are accurate.

Severe Psychological/Mental Health Consequences:

The study identified that these collective experiences of victimisation (perceived negatively, systematic violence, institutional abuse, mate crime and secondary victimisation) significantly impacted on the lives of PWLD. Respondents reported the high risks and actual experiences of:

Fear and Isolation

- “I kept myself to myself really. I did not mix with other people... and I was scared to talk to people. I was scared of what people could do to me, that people could take advantage of me. I felt really vulnerable” (PWLD 02).
- “I was so scared that is why I left the place and moved to a new home (PWLD 08).
- “...feel terrified of going to the bus station on my own” (PWLD 05).

Loss of confidence, identity and self-respect

- “My confidence went down and I felt really depressed (PWLD 02).
- “ It does cause damage to me because my self-esteem goes low, my confidence levels go down too and makes it hard for me to trust women” (PWLD 11).

- “Many PWLD will try to hide their learning disability because they do not want to feel stupid. So what they are doing is ignoring part of who they are. They try to come up as able as everybody else is but you can see that they are not. They will not say a lot about themselves and even lie about where they went to school just to try to blend with others” (PWLD 01).
- I am ashamed to be British to be honest with you. I am ashamed of being a British citizen... (PWLD 03).

Depression

- “It affected me mentally and at times it makes me so depressed. I am taking medicine for it (PWLD 11).
- “Some people with LD go into depression... They may start to isolate themselves, lose interest in activities they are usually interested in, refuse to eat, and sometimes locking themselves in their bedrooms... Some can start self-harming behaviours they have never done before” (Practitioner 09).

Substance misuse, committing crime and detention in hospital/prison

- I turned to drink alcohol, serious alcohol problems starting from 18/19 years of age. This was always out of hours. I also turned to drugs as well and I have changed beyond recognition. ... I would find myself in trouble with the police and that started a vicious cycle which went on and on. But it got terribly worse one year that they even called a psychologist to see me. I ended up being arrested by police and taken to prison for the aggression” (PWLD 10).
- “The victim with LD can become depressed, and then turn to alleviating their depression from alcohol, drugs or self-harming or harming others. This can cause the development of other disorders and destructive behaviours which, in turn, can lead to their institutionalisation in mental health hospitals” (Practitioner 05).

- He trusted the carer with his money and this carer ended up misusing most of it. He was deeply affected and could not come to terms with losing his money in that manner, so the gentleman started a fire which burnt his flat. He ended up in a secure institution sectioned under the mental act because of the crime he committed” (Practitioner 08).

Suicidal ideation

- At one point I had some suicidal thoughts, although I have not attempted to do the actual suicide (PWLD 11).
- “I got depression and became suicidal” (PWLD 03).

In this current research interviews, respondents described how the usually cumulative on-going and often multiple experiences of victimisation can have a detrimental effect on both the mental health and behaviours of PWLD. They indicated that PWLD can have a combination of fear, isolation, feeling depressed and having suicidal thoughts. As a result many find it hard to cope leading to substance misuse, unlawful behaviours (physical aggression, setting fires) and subsequently can end up spending a significant amount of their lives in secure hospitals or prison. As stated by PWLD 10, this can develop into a vicious cycle of being well and unwell and of being in contact with the criminal justice system and/or the mental health hospitals. Hence, it can be concluded that victimisation is a major source of the internal tensions, high levels of trauma and poor quality of life many PWLD experience over prolonged periods of their lifetime.

These findings are in agreement with existing literature on victimisation experiences affecting PWLD. Hastings et al. (2003) concluded that there is a potential significant relationship between life events and mental illness. A literature review by Sequeira and Hollins (2003) looked into the clinical effects specific to sexual abuse. The review reported undesirable experiences ranging from loss of self-esteem, problem behaviours such as aggression, alcohol misuse and depression to more severe conditions such as post-traumatic disorder, personality disorders and schizophreniform psychosis. In a study on the impact of life events and bullying of PWLD, Gunther et al. (2007) found that these can be associated with hyperactivity, emotional problems and behavioural problems. Also supporting the strong empirical base of the association between

psychological/mental health problems, the work of Tsakanikos et al. (2007) which examined the effect of multiple life events on the mental health of PWLD reported personality disorders, depression and adjustment reactions as the main consequences. A similar study (Emerson and Hatton 2007) reported experiences of high risks of psychiatric disorders, in particular conduct and emotional disorders. A more recent study (Northway et al. 2013) found that the experiences of PWLD can range from embarrassment and anger through paranoia and depression to suicidal ideations. Another study (Brakenbridge and Morrisey 2010) found consistent reports of adverse events and potential traumatic experiences among patients with learning disabilities in a high secure hospital.

It is clear from the literature and this current study that the psychological and emotional responses to victimisation are multiple and profound. As the evidence suggests, the continuous and pervasive nature of PWLD victimisation at societal level adds to the scale and complexity of their emotional pain and associated resulting disorders. Hence, it would seem that this bigger picture of their psychological/mental health problems has not been portrayed as such. That is, the role of society, through collective actions of victimisation of PWLD by different members of society and social institutions, in contributing to these problems may yet to be given the robust attention it deserves. According to Duran (2014) an understanding of the overarching underlying historical and life-long problem of social rejection PWLD face can make a difference in our comprehension of the trauma they experience and in turn, the kind of interventions we can develop as a society. This will require professionals and institutions to develop awareness of, and to consider their own contribution towards, the victimisation of PWLD. Equally, this may also require practitioners/clinicians to be vigilant to the possibility of unresolved experiences of victimisation when PWLD are in contact with mental health services.

Reacting to victimisation:

“Putting up with” their victimisation emerged as the main way PWLD adopt to deal with the negative societal attitudes, systematic acts of violence, institutional abuse, exploitation and secondary victimisation. This is shown in the extracts below:

- “I could have packed my bags and left but I would have lost the benefits. I had to put up with the verbal and physical abuse 3 days a week” (PWLD 02).

- “You cannot stop the inevitable, if it is going to happen it will happen. I do not know how to prevent the abuse from women... With all the help I have been given, I still find myself in the same situations over and over again. As I have said, if it is going to happen it will happen” (PWLD 11).
- “There is not much you can do about it. You just have to put up with it and learn to walk away otherwise you create more trouble for yourself” (PWLD 01).

The general consensus among the research respondents of this study is that accepting is a key reaction to their overall victimisation, otherwise they will not be able to cope with life. They talked about ‘putting up with’, walking away and perceiving their experiences as inevitable and as something they expect to take place. This is in line with the theories of hopelessness and helplessness by Seligman (1975). In the hopelessness theory the assumptions are that when people experience prolonged negatives, they expect bad experiences to occur and have no hope that any good will happen. Those affected will believe that their situation is unchangeable and that there is nothing they can do to modify or transform their situation.

In the learned helplessness theory, the individuals affected feel helpless to avoid negative experiences, they have learned from previous experiences of no control over the cause of their victimisation and no control over the outcome of their situation. They will feel they are trapped and unable to escape the pain they experience and that their own actions will not have any effect (Abrahamson, Devine and Hollon 2012).

Conclusions:

The notion of victimisation as a form of oppression was able to accurately represent the key experiences of maltreatment PWLD face. The integrative approach of this notion, which differentiates it from Young’s framework, allowed a simpler presentation under the broad term Victimisation that allows the interconnection of these experiences: negative attitudes, acts of violence, systematic abuse (institutional and mate crime), secondary victimisation and psychological/mental health consequences. The evidence shows that victimisation of PWLD is systematic and pervasive. It involves a wide range of perpetrators across society and occurs

everywhere PWLD interact with members in their communities. Their reactions to and the consequences of these experiences to PWLD are far reaching with major impact on their mental health which can only exacerbate their victimisation. It would seem that addressing these problems is complex as multiple factors are involved. It would also seem that at the heart of the problem is the limited progress in achieving fundamental changes in society's attitude towards PWLD. There is some agreement in that previous efforts have targeted practitioners working with PWLD and left out the majority of the population, in particular members of the public. But even the targeted professionals are among the perpetrators of victimisation of PWLD suggesting that this may not be a simple issue of awareness or negative attitude, i.e. other factors may be at play. However, any intervention should carry with it members of the public and will require a long term commitment to deal with this problem at this large scale level.

CHAPTER 3: MARGINALISATION AND VICTIMISATION

INTRODUCTION

Chapters 1 and 2 have attempted to reformulate Young's (1990) framework of oppression from five elements down to two: Marginalisation and Victimisation. This was achieved by enhancing the nature of marginalisation as discussed by Young and through showing that the other elements: exploitation, violence, powerlessness and cultural imperialism can be more usefully understood under the heading Victimisation. Hence, the aim of this chapter is to look at the findings in a much broader context providing an overview of this new form of oppression principally defined by a symbiosis of marginalisation and victimisation of PWLD. This wider context will be explained through three theoretical factors: a) Internalised oppression; b) Structuration; and c) Power relations and powerlessness. It will be argued that the outcome of these three forces: internalised oppression, structuration and powerlessness, result in creating an oppressed (marginalised and victimised) group located in the lower status social hierarchy, best described as the underclass.

Internalised Oppression: as a Factor that Perpetuates Marginalisation and Victimisation:

Internalised oppression is a term used to the “involuntary reaction to oppression which originates from outside one’s group and results in group members loathing themselves, disliking others in their group, and blaming themselves for their oppression - rather than realising that these beliefs are constructed in them by oppressive socio-economic political systems” (Rosenwasser 2000:01). Pyke (2010) identifies internalised oppression as a hidden and subtle key form of oppression whose role in suppressing others cannot be underestimated. The author points out that this has remained the most neglected key component of oppression and as with many authors, was overlooked in Young’s (1990) Framework. Two main points make internalised oppression relevant to the new form of oppression: marginalisation and victimisation, developed in this study.

The first point is that internalised oppression is a major consequence of both marginalisation and victimisation processes affecting PWLD (Pyke 2010). In other words interrelationship between marginalisation and victimisation culminate in internalisation of the oppression experienced. Evidence from this study suggests that the sustained and life-long subjection to both marginalisation (being abandoned by their families, segregated in SEN schools, receiving poor quality education and lacking opportunities in skills training critical for gaining credible jobs) and victimisation processes (being called names and spat at, physically attacked, financially abused and sexually abused) can lead to negative-images, low self-esteem, mental health problems and a poor socio-economic status (Quarmby 2008). These products of oppression, associated with feeling inferior or less human, become the integrated psychological make-up of the affected PWLD which engender an overwhelming sense of hopelessness and helplessness highlighted by research respondents of this study. It would seem that the hopelessness and helplessness generated is central to PWLD in believing that their oppression (marginalisation and victimisation) is inevitable, irreversible and that their efforts to intervene are of no use. Hence, going along with their mistreatment is seen as the only alternative to survive or mechanism to cope with their inability to overcome the complex forces of interrelated marginalisation and victimisation (Freire 1970; Campbell 2007).

The second point is that internalised oppression is a major component and fundamental factor necessary for maintaining and perpetuating both the marginalisation and victimisation of PWLD by society (Williams 2012). It is perceived as an important pillar standing upon which marginalisation and victimisation processes can continue in the mind without the oppressor being physically present to enforce acts of oppression (Love 2002). According to Freire (1970) this key phenomenon can

only happen when the oppressed go beyond simply feeling hopeless and/or helpless. The author points out they will also need to start believing that the stereotypes and misinformation communicated about them are true. Instead of seeking to liberate themselves, the victims identify themselves with those who oppress them even to a point of wanting to be like them. Evidence in this study and explanations in literature suggest that it is this characteristic of oppression (marginalisation and victimisation) that allows the oppressed to turn against themselves. This can be through becoming convinced about their unfitness, acting in ways similar to how society mistreats them as well as feeling ashamed and hating being with those in their own social group. Examples include reports by some respondents in this study distancing themselves from other PWLD through avoiding any contact with them and trying by all means to emulate those without learning disabilities so as to 'blend' in with other members of society. Others expressed being happy with the identities imposed on them (learning disabilities, not good enough) and believe they are lucky to have the little they possess in life.

Here, it is the power of the marginalising and victimising processes in successfully imposing society's negative ways of treating PWLD that its views are accepted by PWLD as representing their own interests, as the norm or something they deserve (Pyke 2010). Duran (2014) describes this targeting of the mind as the most potent weapon of oppressors in consolidating and maintaining their oppression. Consequently, PWLD will continue to behave and function in ways that reinforce a cycle of their own marginalisation and victimisation with little or no resistance from them (Adam, Bell and Griffin 1997; Pyke 2010). This is seen in how such experiences can limit their choices and how they are forced to hold themselves back from leading fulfilling lives. For example, where a child is taken into care, parents with learning disabilities may decide not to have another child because they believe they are not good enough parents; people deciding not to go into sexual relationships because they believe it is not normal for PWLD to do so; people accepting as normal staying in-doors or visiting public places when there are few or no other non-learning disabled people around and people seeing no point in completing their secondary education in SEN schools because they believe it will not make any difference to their lives.

Raising the profile of this dimension of oppression should help develop a deeper understanding of the role of society and the mechanisms it uses in reproducing the marginalisation and victimisation of PWLD. This includes understanding how it becomes an important ingredient of a mechanism

that allows passing of oppression from one generation of PWLD to another throughout history (Freire 1970; Atherton 2005). This encompasses comprehending how internalised oppression weakens PWLD's ability to resist and escape their marginalisation and victimisation. Thus, this notion directs us to consider how best PWLD can be effectively supported and empowered in such situations where their voices have been subtly silenced and any efforts to make changes to their lives will be determined by schemas and meanings dictated by those who oppress them (professionals, care institutions, individuals). Furthermore, an awareness of this notion can have clinical benefits. This might bring useful insights into how the phenomenon influences PWLD's thoughts, attitudes towards self and their oppressors, and behaviours. Also, this can contribute to enhance the appreciation of the different aspects of trauma affecting PWLD and its effects beyond the original traumatic experience emerging from their oppression (Duran 2014). As pointed out by Watermeyer and Gorgens (2014) this may open up the potential for developing strategies that can unlock the trauma arising from marginalisation and victimisation. Finally, it is important to acknowledge that internalised oppression would not have existed without the real external oppression produced through collective actions of agents and the social structures they interact with, as will be detailed in the structuration section that follows.

Structuration: as a force that binds marginalisation and victimisation processes:

The Structuration Theory will be used as an explanation tool to account for the interrelationship between the marginalisation and victimisation processes affecting PWLD. This is a sociological theory developed by Giddens (1984) which attempts to overcome the gap between the prevailing schools of thought: structuralism and voluntarism. The theory rejects structuralists' notions that places emphasis on societal structures as the primary influences of the reconstitution of society and minimises the importance of the active role of individuals in producing their social reality. It also rejects voluntaristic theories for underestimating the role of structures and placing emphasis on the role of individuals in social change (Giddens 1998; Lamsal 2012). Structuration Theory takes the middle ground and acknowledges that both social structures and human actors influence each other without giving primacy to either. On one hand, social structure (traditions, institutions, moral codes and other sets of expectations) shape the individual or social groups by means of use of rules and resources that either constrain or facilitate human activity. On the other hand, human actors are seen as active participants that enable the creation, reproduction or substitution of structure through socially constructed values, norms or social acceptance (Lamsal 2012). Hence, according to

Giddens, social structures can only exist insofar as they are continually produced and reproduced in social activity through acts of individual agents. In other words structuration refers to the methods by which society is changed (Giddens 1984).

The relevance of the Structuration Theory to the current study is its emphasis on understanding the symbiotic relationship between the collective actions of individual agents and the power of social structure in creating an environment of marginalisation and victimisation (oppression) affecting PWLD. This study argues that at both social agency and social structural levels, marginalisation and victimisation processes are linked. Although production of one process can be dominant at each of the levels, the influence of both marginalisation and victimisation in the reconstitution of the oppressive life experiences of PWLD cannot be separated as they are inextricably intertwined. Thus, it would seem that the more marginalised you are, the more you will be victimised. However, for the purpose of analysis the processes will be presented separately at agency and structural level.

At a social structural level, this refers to how the oppression of PWLD is institutionalised throughout systems and society (Baron 1998). This is about recognising the power of rules, resources, institutions (produced rules and resources) and social systems (reproduced practices) in shaping the way society at large oppresses PWLD via both marginalisation and victimisation processes (Giddens 1998). The findings of this study suggest that marginalisation of PWLD is the dominant form of oppression created and maintained at this structural level. Giddens (1984) identified three types of structures which help to explain the close interactions between these agencies and social structure and the dialectical relationship between marginalisation and victimisation. The first type of structure is signification: which produces meaning through organised webs of language. Such a web of language, including labels that describe PWLD (idiot, mentally retarded, learning disabilities) and vocabulary used to interpret their care and social needs (vulnerable, dangerous, lacking capacity, disabled), becomes a major resource through which to marginalise PWLD and in turn victimise them (Galvin 2003). This language which interprets PWLD as largely unable, a burden and people who need to be cared for, is produced and reproduced in higher educational institutions by academics and in medical institutions by specialist professionals. This is communicated in powerful social systems such as specialist journals, diagnostic criteria manuals and government policies. In this way the language used about PWLD

and how this is interpreted becomes the structure which facilitates society to take actions that marginalise and victimise them.

The second type of structure is legitimation which “produces a moral order via naturalisation of societal norms, values and standards” (Lamsal 2012: 114). Based on this, it would seem that oppression is built around what is understood to be the norm (what is considered socially normal or acceptable). These norms are reproduced over many years usually in a pair of rules that define what is normal and what is not. Once they become stable and accepted (as normal or not), they shape how individuals interact with each other and with the wider society (Giddens 1984, 1998). Linking this with the signification structure and referring back to the findings of this current study, it would seem that it has become the norm to portray PWLD as largely abnormal biologically and socially. Conforming to this norm, a whole range of rules (policies, guidelines, Acts) and resources (care institutions including hospitals and residential homes, special educational needs schools, professionals) have been put in place to cater for these abnormalities in some ways that have restricted life opportunities for PWLD (Wheeler-Brooks 2009). The fact that these processes occur mostly through formal structures seems to legitimise the discrimination, segregation and life-long poor socio-economic status (Mullaly 2002; Hardiman, Jackson and Griffin 2007). This is further explained under the structure domination.

The final element of structure is domination. This refers to the “production of power originating from the control of resources” (Lamsal 2012: 115). Here the focus is the interaction of human actor and structure as opposed to the relationships between means of production as suggested by Karl Max. Resources are seen as the vehicles of power and a form of authority that can be used to oppress others. Wilson (1994) suggests that once the oppressive structures are in place those oppressed will be more constrained than they will be enabled by these structures. In the case of PWLD, it would seem that their marginalisation by society is through resources such as education, social welfare system, health care system, criminal justice system, employment institutions and the family (Hardiman, Jackson and Griffin 2007). The evidence suggests they experience systematic and permanent lack of opportunity to benefit from them like any other citizen. They also lack the ability to influence or act in order to bring about positive changes in these structures that oppress them (Giddens 1984; Richards 2009). In this study, it is reflected by the type of schools they go to and the type of education they receive, the type of stores they shop at and the kind of material

belongings they possess, the kind of jobs they take and the wages they receive. It is also the kind of family life they experience and how they are brought up, the kind of accommodation they live in during their adulthood and the kind of public places they go and how they are treated at such places (Barone 1998; Langston 1995). All of which indicate deep social problems affecting a whole social group with learning disabilities.

At social agency level, this refers to the oppressive social interactions PWLD have with the non-learning disabled population which in this study are predominantly acts of victimisation (Hardiman, Jackson and Griffin 2007; Baron 1998). These are not just negative interactions in which a few mal-behaved individuals in society constrain the lives of PWLD. They are interactions in which a wide range of members of society reproduce collective negative actions in line with the influences they receive from the existing systems, institutions and the dominant ideology which create an environment of oppression that empowers others to victimise PWLD. The influences incorporate the beliefs society has about PWLD, the value society give to PWLD, the way society has historically/traditionally treated PWLD and the shared understanding of how PWLD ought to be treated (Thomas and Woods 2003; Lamsal 2012). Evidence shows that members of the public are among the key agents that victimise PWLD through their acts of invalidation found in looks, words and actions. These acts include hardened stares, hurtful comments (what are they doing here?), ignoring PWLD, not willing to share public spaces with them (members of the public walking out of restaurants), physical assaults and damage to property of PWLD. Hence, the respondents of this study have been calling for more comprehensive policy interventions that target changing attitudes and behaviours of the general public towards PWLD.

The victimisation interactions can also occur with practitioners who work with this social group in community settings (Encyclopedia Britannica 2015). This is a typical example of interaction in which one agent dominating the other is made possible through existing social structures and systems. Practitioners such as health and social professionals use structural principles, rules, legislation and guidelines that mediate institutionalised patterns of interactions that promote their control of the lives of PWLD (Dowson 1997). Evidence shows that in a significant number of cases, practitioners have used this control to establish a wide range of victimising interactions with this social group (DH 2012). As an example of part of doing their job, practitioners have been reported for excessively controlling sexual relationships between PWLD and unnecessarily taking into care

children of parents with learning disabilities. Like members of the public, they have also been reported for physical assaults, neglect, financial exploitation and sexual abuse of PWLD they look after. Hence, as identified by Northway (1997), there is need for professionals working with PWLD to be aware of their contributions towards oppressing PWLD and to develop strategies that assist in reduction of the social problems they face in their daily lives.

Giddens (1984) suggested that his structuration theory does not only serve to provide insights into the complex picture of the symbiotic relationship between agency and social structure, but also serves as a framework through which change can be achieved. The author points out that interactions are not fixed and that no system, institution or structure is closed. Human agency's influence can help to substitute or replace some or all aspects of the structure. These insights should allow researchers and policy makers to take a close look at how the experiences of oppression are continuous, pervasive, interact at different levels and entrench PWLD in a cycle of oppression (Hardiman, Jackson and Griffin 2007). This should be the basis from which to identify factors within both structure and agency that help to disrupt the recursive processes that maintain the oppression of PWLD (Wheeler-Brooks 2009). For example, changes can involve: a) Finding and establishing new language or dominant ideology which does not carry the same negative connotations as the current language/ideology being substituted in order to communicate more positively about PWLD across the institutions of society; b) Increasing investment in improving means through which PWLD can access and benefit more from the existing institutions such as the family, education and labour market; and c) Ensuring that PWLD become part of the human agency that can actively influence the structures and other agencies that affect them.

It is clear that both internalised oppression and structuration are essential factors in the marginalisation and victimisation processes of PWLD. Both factors manifest in the context of unequal power relations seen as the cornerstone of the historical powerlessness PWLD endure. Hence, power relations and powerlessness will be tackled separately in the next section.

Power Relations and Powerlessness: components of marginalisation and victimisation:

This study shows that the combination of marginalisation and victimisation processes is a central component in the creation and sustenance of social powerlessness among PWLD. It would seem they are the overarching social forces that subject PWLD to power relations of subordination to and

domination by a system of social institutions or networks (Morgan, Letnar and Lindsay 2010; Foucault 1982).

As suggested by Foucault (1982), this powerlessness can be best explained focusing on the day-to-day interactions between PWLD and the system of institutions they interact with. A series of powers within the system such as those of the family, education, labour market, professionals and members of the public, each contribute to weaken the social position of PWLD. For example, the family abandoning their children with learning disabilities, the professionals controlling the lives of PWLD, labour market not able to offer employment opportunities to PWLD and the members of the public victimising PWLD are some of the means in which the multitudes of institutions disempower PWLD. They are systematic actions that limit or prevent PWLD from participating in communities on equal terms as the non-learning disabilities population and make them unable to influence what happens to their lives.

While each element of the system (e.g. education, labour market, professionals, members of the public) can individually marginalise and victimise PWLD, the driving forces behind their oppressive mechanisms are anchored in society's attitudes and beliefs towards PWLD (Foucault 1982). In other words, the behaviours of these series of institutions or system of social networks is a reflection of the power relations between the general population/society and PWLD. For example, the controlling powers professionals have on PWLD is in line with how society believes PWLD should be treated and this kind of control could not have survived if the society had different beliefs and attitudes towards this social group. The discrimination of PWLD in public spaces prevails as this does not only find support in the other multitude of institutions but is also spread throughout the whole society (Foucault 1982). From this standpoint, it is clear how the social powerlessness of PWLD is deeply rooted in society's perspectives towards them and created and sustained by its system of institutions through marginalisation and victimisation.

The research data strongly suggests that powerlessness creates inability or socially disables the individual and social group as a whole, they will lack the ability to change their life situations. In this case having received poor quality education, having no qualifications, being deficient in job related skills and without access to shared community resources, PWLD are restricted in terms of self-development and self-determination (Adams, Bell and Griffin 1997). They are left with no effective means to overcome the often complex processes involved in their marginalisation and

victimisation to challenge their oppressors (Cudd 2006; Harvey 2010). Socially disabled in this manner, their voices remain suppressed and hence, they will lack the power to define their own life needs as well as lacking the ability to act upon the problems they face in relation to these needs (Asch 1986). Consequently for many PWLD, they will not be able to achieve the required social and economic mobility needed to transform their lives. This reinforces Blow's (2008) argument that community care policy has not done much to empower PWLD and that the language of empowerment has significantly helped to camouflage the oppressive experiences which have continued to happen among PWLD. The author argues that real empowerment can only happen when the oppressed are able to influence the individuals, the institutions and communities that affect their lives, which PWLD may be a long way from achieving.

The consequence of powerlessness can be even stronger when this is further entrenched psychologically and starts to allow PWLD to disempower themselves (Freire 1981). Connecting well with the notion of internalised oppression, PWLD will cease to have the willingness to fight for more control and influence as they believe that nothing can change. The powerlessness experienced is perceived as intrinsic in their medical condition rather than in their social oppression (Asch 1986). Hence, they will accept their lack of power as necessary and normal. This will be reflected in their lack of confidence and self-esteem, lack of self-respect, high levels of anxiety in public areas and the general presentation of inferiority complex which respondents have highlighted in this study (Sybol and Anderson 2011; Galvin 2003).

Underclass as Explanation to Account for the Resultant Social Status of PWLD:

The outcome of internalised oppression, structuration forces and powerlessness is to create an oppressed (marginalised and victimised) group who are located within the lower part of the hierarchical social status. According to the research respondents of this study, PWLD are positioned at the bottom of the social hierarchy. They have not been accepted as full human participants and are seemingly the least valued members of society the public would want to interact with (Scior 2011; Staniland 2010). From the results, they lack in all areas that are associated with power and privilege such as employment (associated with skill and power), education (associated with knowledge) and marital status (Hollingshead 2011). But they have also been discriminated against in public spaces/places and in their home such that the totality of all this oppression can best describe a social group socially situated in the underclass. According to Bryan (2007), the sheer

number and combination of these exclusionary factors (societal negative attitudes, poor social relationships, lack of community integration, unemployment and violation of rights) make PWLD to be one of the most disadvantaged social groups in society. The author believes their situation is best described by the term 'Underclass'.

Haitsma (1989) defines the underclass as those people who have a weakened connection to the mainstream labour force and whose resulting social situations further weakens their link to participation in the formal economy. The author emphasises that chronic poverty is a key component of an underclass which results from the permanent non-work or weak formal labour force attachment. Wilson (2006) suggested that among several other factors, dropping out of school and dependency on welfare benefits are some of the key characteristics of those defined as the underclass. The author then defined the underclass as those members of society who suffer from minimal education, long term unemployment and social isolation, as well as lacking community safeguards and access to essential resources. The author believes that the defining aspect of the underclass is the lack of employment opportunities and social support. Field (1990) shared similar views and added as an important characteristic of the underclass the inability of PWLD to experience socio-economic mobility, which is necessary for them to escape the welfare system or the cycle of poverty.

It is reasonable to suggest from the findings that PWLD are socially situated within the underclass. This social conception describes those who experience poor education, lack of skills, long term exclusion from the labour market, low paid jobs, dependence on state welfare benefits, material deprivation and lack of socio-economic mobility. However, PWLD seem to experience a social status that is more socially undervalued living somewhere beneath the underclass (Whittaker 2013). For the research respondents of this study, it is the depth of the unacceptance of PWLD by society that makes their situation different from other poor people or social groups. Perceived as unable, useless and as dependants, and as the least desirable people to interact with, very little has been done to maximise their contribution in society (Staniland 2010).

Although their accommodation, shelter, food and other basic needs can be met (Department of Health 2012), they are dependent on others to provide for them. This state of powerlessness has resulted in a pervasive controlling nature over their lives by different members of the society

(family, professionals, friends, members of the public are all agents of control). Beyond what happens with other disadvantaged groups is the control of their sexual relationships, of their own families and control of their children (Office for Disability Issues 2009). They are simply people with no stake in society and with no power or skills to do anything to change their situation (Whittaker 2001; Bryan 2007).

The psychosocial consequences of these lived experiences can be devastating and can impact on mental health and their overall well-being. This includes developing that sense of despair, hopelessness, helplessness (Thomas and Woods 2003) and a lack of sense of belonging (Joel and Wright 1993), all of which have been highlighted by the interviewees with learning disabilities themselves. This was more pronounced in their collective and consistent expression of a sense of depression; the extent of its impact may not be known.

Overall the concept of underclass only starts to explain the difficulties this social group face. According to Haitsma (1989) and Wilson (2003), the use of the concept helps to remove the focus on the individual, thus enabling the scrutiny of the structural mechanisms that play a pivotal role in limiting life opportunities and forcing certain social groups into lives of deprivation. So far it can be concluded that 1) They are part of the underclass; 2) Their social status is even lower; and 3) This has significant psychosocial impact on their everyday lives. However, Cameron, Cabaniss and Texeira-Poit (2012) urge a cautious approach when using this notion of underclass. The authors point out that there is a danger that if inappropriately used, the concept can reinforce the prejudiced views we are trying to reduce. But by not recognising their true social status we do the same.

Conclusions:

Oppression of PWLD consists of symbiotic processes of marginalisation and victimisation which are deeply rooted in a system of forces of structuration, power and power relations and internalised oppression. An understanding of their oppression will not be complete without the fundamental insights of how these forces collectively disempower and create a web of multiple social problems PWLD face, which are maintained from one generation to another. The resultant outcome is underclass social status of a social group with no stake in society. Addressing this complexity will require nuanced interventions that match the intricacies involved at both structural and human agency levels.

CONCLUSIONS

INTRODUCTION

This research study explored the oppressive experiences endured by PWLD living in the community. It addressed questions regarding the nature, causes and consequences of experiences of oppression faced by PWLD during the course of their everyday lives. The purpose of the project was to help practitioners and scholars to develop a better awareness of the social problems PWLD continue to endure in an attempt to contribute to a holistic approach of understanding the multiple needs of this group. In this study, the term oppression was defined as the various and deep rooted forms of harm or disadvantage a person or group of people suffer, following systematic and unjust

treatment during the course of their interactions with other individuals or groups in society (Harvey 2010; Young 1990).

The chapter is organised into five main sections. Section 1 starts with the synthesis of the results, bringing together the key research findings of this study; Section 2 discusses the strengths of the study; Section 3 highlights the major limitations; Section 4 explores the policy and practice implications; and in Section 5, the chapter concludes with some suggestions for future research.

SYNTHESIS OF THE STUDY RESULTS:

The study reformulated Young's framework of oppression from five forms of oppression down to two forms: Marginalisation and Victimisation. The evidence suggests that these forms of oppression exist in a symbiotic relationship that traps PWLD in a web of oppression. They are interwoven throughout social institutions as well as imbedded within individual consciousness. From the study, it can be concluded that PWLD have remained a highly oppressed invisible social group. Their marginalisation is extraordinarily multi-layered and pervasive across society and its impact is such that it affects every aspect of their lives (education, employment, accommodation, family life, public life experiences, experiences in private and public institutions and social status).

It would seem that it is the very structures or systems created in order to provide them with life opportunities, support and protection, which interact at different levels to maintain the marginalisation of PWLD. From the respondents' stories, the overall negative impact of this on their lives is wide ranging. These include lack of paid and credible jobs, lack of credible education, severe material deprivation, abandonment by families and lack of social relationships and recognition. This has a long-term damaging effect on their self-esteem and mental health. More so, they lack the means to break the cycle of their marginalisation and consequently, can predispose them to victimisation by society.

The study, both confirmed and added to the findings from previous studies that victimisation of PWLD is widespread. PWLD continue to experience a broad extent of different types of victimisation ranging from verbal and physical abuse, financial exploitation to direct discrimination in public places. These acts of victimisation can be carried out by any member of society wherever PWLD live. It would seem that these kinds of experiences play a significant role in shaping their

daily lives as they attempt to avoid or confront their victimisers and try to cope with their unlimited victimisation. As with experiences of marginalisation, the consequences of on-going victimisation can be detrimental to the well-being of PWLD.

At the heart of both marginalisation and victimisation of PWLD are the negative societal attitudes, which the research respondents believe are the single major cause of their oppression. These are seen as the driving forces underpinning the acts of violence and discrimination against and exclusion of PWLD. The consensus among respondents is that little is being done to tackle this key issue and they believe that until this problem is decisively addressed the oppression of PWLD is likely to be prolonged. Other factors such as lack of education and work related skills and the general powerlessness of PWLD have been identified as key reasons for why their lives remain overly controlled by protective families, professionals and the learning disabilities care industry.

While there is a general sense of hopelessness and helplessness in terms of finding solutions to the problems faced, there is a significant number of PWLD who believe in PWLD themselves taking the lead (with support where necessary) in campaigning for changes in the way they are treated by society in general.

STRENGTH OF THE STUDY:

This phenomenological study provided an opportunity for accessing the perspectives and experiences of PWLD living in the community whose voices would otherwise have remained silent. Participants were recruited from different regions of the United Kingdom (London, Cardiff, Buckinghamshire, Northamptonshire, Derbyshire and South Yorkshire), which helped to capture the perspectives of PWLD across England and Wales. While the sample was small, the selected respondents were the most appropriate participants with the experiences and opinions that addressed the study research questions.

It can be argued that the study was not only able to confirm previous findings but it was also able to increase insight into the social complexities involved in the daily life experiences of PWLD. The exposed nuanced forms of oppression and their consequences highlight the call for a more balanced focus and integrated approach when looking into the well-being needs of individuals with learning disabilities. A focus that emphasises on healthcare alone might miss key aspects of the problem affecting them and thus may not be able to provide adequate relevant interventions. This social

insight should, therefore, ensure that future supporting policies treat social care needs as a critical element of any holistic approach that considers and responds to all factors relevant to the care of PWLD.

Furthermore, the information generated can contribute to highlighting the importance of understanding PWLD in terms of oppression and not simply in terms of their impairments. The information can also be utilised to understand the unequal distribution of victimisation among social groups in relation to oppression. It is expected that the findings will be transferable to the situations of many other PWLD throughout the United Kingdom and that policies and other useful responses to oppression can be drawn from this study.

LIMITATIONS OF THE STUDY:

The scope of this study has its own drawbacks. A limitation of this study was the opportunistic sampling due to the recruitment difficulties encountered. Although the opportunistic sampling provided the selection of information-rich cases, the sampling technique introduced biases such as under-selecting female participants with learning disabilities, over-selecting white male participants (nine males and 2 females) and missing PWLD from ethnic minorities. Findings may not reflect the views of females and PWLD from ethnic minority backgrounds. Also, the sample excludes people with severe and profound learning disabilities, mainly due to the lack of material and financial resources needed to meet their communication needs. The study did not offer the opportunity to compare and contrast the views of respondents with learning disabilities against the views of practitioners which might have increased the depth of understanding of the oppressive experiences affecting PWLD.

POLICY AND PRACTICE IMPLICATIONS:

The findings of this study hold important policy and practical implications for improving the lives of PWLD. These are related to the White Paper, Valuing People: A New Strategy for Learning Disability for the 21st Century, which has been the main piece of legislation driving forward policy on PWLD for the past fourteen years (DH 2001). The paper sets out a programme of action to improve the lives of PWLD based on four key principles: Rights, Independence, Choice and Inclusion. Taking a life-long approach, it proposed a range of strategies that reinforce community care, increase life chances of children with learning disabilities and provide opportunities for PWLD to lead more fulfilling lives as adults. The goal was to achieve, among many other

intentions, improvements in education, employment, housing and support that PWLD and their carers receive (DH 2001). This was taken further in the Government Protocol: Putting People First (DH 2007), which outlined shared aims and values between state, service providers, professional leadership and regulators in developing a new adult social care system. The emphasis was on personalisation, person-centred approaches and personal budgets with the aim of enabling more independent living and the best quality of life independent of the person's disabilities (DH 2007). As a follow-up undertaking, Valuing People Now (2009) was launched as a three year strategy to take forward the delivery of the policy outlined in Valuing People (2001). Post-16 education, employment, relationships and right to family life, support for parents with LD and safety in the community and at home are among the issues given priority in this new strategy (DH 2009).

Policy Implications:

The evidence from this study point to the fact that PWLD continue to experience layers of marginalisation and pervasive victimisation. This evidence shows that the current policies have not made the anticipated impact, thus, suggesting the need for their review in four main areas: Negative societal attitudes towards PWLD; Experiences of family life by parents with learning disabilities; Experiences of education; and Experiences of employment.

Negative societal attitudes towards PWLD:

Although the current policy highlights society's negative attitudes as being at the heart of the marginalisation and victimisation of PWLD, there is no clear policy on how this problem can be addressed (Ritchie 1999; Turning Point 2004). The policy initiatives to change the way we treat PWLD predominantly target professionals working with PWLD mainly in education, health and social care sectors (DH 2001). The rest of the population does not take an active role in this and yet the success of the implementation of the inclusionary policies for PWLD dependent heavily on their attitudes (Turning Point 2004). Ritchie (1999) explained that any changes for better treatment of any oppressed group will not be sustainable if there is no parallel change in the attitudes held by society towards that group. Hence, lack of progress in changing society's attitudes will be reflected in the limited progress in all other aspects of PWLD's lives.

Respondents of this study believe the way forward is educating the society to address negative attitudes associated with "focusing on what PWLD cannot do", "ignorance" and "not knowing what

learning disabilities is about” (PWLD 01, 02, 03, 10). Also perceiving education of communities as the potential solution, Krahe and Altwasser (2006) highlighted that targeting the cognitive foundation of society’s prejudicial attitudes towards vulnerable groups is central to achieving longer lasting changes in perceptions necessary for their acceptance in society. In their study, they concluded that combining both cognitive intervention through information and the physical presence of the prejudiced group in communities was more effective in producing greater change in attitudes and integration compared to the physical presence or contact intervention on its own.

Therefore, as a possible intervention, this study proposes large scale education programmes that aim to educate, inform and make members of the public aware of the way they treat PWLD. As suggested by the respondents themselves, this may include:

- Using the media (television and newspapers) for clarifying misconceptions about learning disabilities, highlighting how they continue to be oppressed and demonstrating the importance of respecting their rights like any other citizen.
- Promoting and/or funding effective campaigns by PWLD themselves.
- Using role models with learning disabilities to highlight and focus on their capabilities rather than inabilities and disabilities.

Experiences of parenting and family life for PWLD:

Respondents highlighted that they did not receive explanations of why their children were being taken away. As a result they did not know what they did wrong and this left them deeply hateful. There is no support given to help parents cope and come to terms with their loss. For example, a mother attempted to commit suicide walking in the middle of a motorway without looking at what was coming from both sides of the road. She only got support from her husband who was also overwhelmed by this experience. Parents expressed being further devastated when they could only see their children three to six times a year and when told that they were not supposed to show any emotion towards the child. This was their experience despite the fact that they had not been accused of having done anything wrong. This was echoed by the House of Lords, House of Commons Joint Committee on Human Rights (2008) which pointed out that professionals may not be following available guidance appropriately and in the process violating both parents and children’s right to family life. The committee reported that, on many occasions, decisions are taken without adequate information and without testing parents’ abilities. This is the case, yet the number of parents with

learning disabilities is increasing and more are likely to be exposed to similar experiences (Aunos et al. 2008; McKenzie 2014). Hence, the following proposals should help improve best practice in this area:

- Guidance on assessing the parental skills of parents with learning disabilities should be based on the assumption they should be able to look after their child, unless proved otherwise.
- Where there is no evidence of abuse or neglect, it should be explicit in the guidelines that all the necessary support and parental skills training should be provided before children are taken into care.
- Where children are placed into care, there should be clear guidelines about how the relationship between child and parents should be maintained. This includes clarity on frequency of visits and other forms of contact.
- Where children are taken away, both parents and children will need on-going support to come to terms with their separation.
- Professionals involved will need further training in dealing with parenting and family life issues among PWLD.

Experiences of education

In education the current policy aims to extend to families/parents of children with learning disabilities the opportunity to express preferences for the school they wish their child to attend and widening the institutions for which such preferences can be undertaken. The identification and assessments of the needs of those who require further support than normally provided will be given priority. In addition, the policy aims to provide a more joined-up approach to enabling support into adulthood (Department of Education 2013). While these proposals are essential, they fall short of addressing some of the major concerns raised in this study by PWLD themselves. Respondents were not happy with both the institutional aspect of these schools (segregated) and the quality of education offered in these schools, as well as the stigma attached to attending such schools. They do not see any justification for their existence and hence, call for their closure. This is in line with the Ofsted (2010) report, which concluded that the special needs of the majority of children can be met in mainstream settings.

This study proposes that:

- It should be assumed that each child benefits from mainstream schooling unless proved otherwise. Rules regarding placing PWLD in SEN schools should be tightened and placing pupils in such schools should be seen as the last resort which should only be done where there is no other alternative.
- The emphasis should be ensuring that the child's educational needs are being met by focusing on improving the quality of teaching and learning for all rather than the emphasis on providing a SEN statement.
- The voice of PWLD in this area will need to be taken seriously as they have raised fundamental issues at the crux of their long-term oppression.

Experiences of employment:

With regards to employment, the current policy 'Valuing People Now' (2009) seems to be placing the required emphasis on employment and aims to ensure that record high numbers of PWLD are in paid employment. A wide range of government initiatives have been put in place to address PWLD employment problems. These include: Access to Work scheme which provides advice and practical support to disabled people and their employers to overcome work difficulties related to disability; Connexions Advisers; Disability Employment Advisers, who assist with finding and keeping jobs; and WORKSTEP which provides support for disabled people who have more complicated difficulties with getting and keeping jobs. But many PWLD and those who support them are not aware of the availability of such provisions and where they do, employment may not be seen as an integral part of the support or care system (Department of Works and Pensions 2013). While the emphasis on achieving record high numbers of PWLD in employment by 2025 is welcome, the policy falls short of how it will adequately address the problem of lack of training and skills necessary for the uptake of credible and better paid jobs.

The following will be proposed as the way forward:

- To ensure that employment is seen as part of PWLD's care packages.
- To design and/or to adapt schools and further education curricula to match with local jobs.
- To widen the areas of supported employment and the relevant expertise in order to cater for the heterogeneous abilities of this group.

- To find better ways of making information about supported employment readily available to PWLD.

Implications for Practice:

The findings of this study provide several contributions to practitioners' understanding of the nature, causes and consequences of the oppressive experiences affecting PWLD. Considering that the practitioners have been identified as among the main sources of this oppression, it is anticipated that they can develop the required awareness and acknowledgment of the social problems PWLD face in their daily lives. This will involve understanding that marginalisation and victimisation are major forms of oppression that restrict and disable the lives of PWLD. This also involves developing deeper insights into why these social injustices to PWLD continue to prevail and needing different approaches that can guide to transform the way society treats PWLD. As pointed out by Northway (1997), this awareness should enable the practitioners to reflect on their everyday engagement with PWLD, focusing on how in their roles and the institutions they work for, can contribute to the oppression of PWLD. This should possibly influence them to take the necessary actions to reduce their own contribution as well as to be able to challenge others involved in marginalising and victimising this social group. This resonates well with Leblanc's (1997) view, who believes that with such understanding, professionals should be in a position to advocate for increased government commitment to providing resources on a larger scale to address these deep injustices affecting PWLD. The author also believes that insights in oppression can also allow professionals to be more conscious about the labels they give to and which are used by PWLD, thus, seeing the need for labels that should be related or contribute to the fight against their oppression rather than reinforce it.

Central to this awareness of oppression of PWLD is the understanding of the continuum of disability where the role of both impairment and society in oppressing or disabling PWLD is acknowledged. As pointed out by Thomas (2004), the study highlights the significant role society plays in oppressing this vulnerable social group. It is a distinction which should help practitioners and scholars to identify the critical determinants of oppression and the general well-being of PWLD. It is hoped that such insights can help reinforce the commitment by practitioners to move the notion of "Oppressive Experiences" affecting PWLD higher up the public agenda in order to achieve widespread awareness at societal level. They can use their unique positions to strengthen

the support they provide to PWLD in their campaigns against their marginalisation and victimisation. This can be through: Supporting PWLD to undertake presentations at local, national and international conferences; Assisting PWLD to mobilise and engage in effective street campaigns; Supporting PWLD to use local and national media to communicate their views and experiences to the wider population; and adopting more aggressive strategies in promoting use of concepts and implementation of user involvement approaches.

Clinically, Duran (2014) believes that lessons can be learnt about the kind of traumatic experiences PWLD endure. Based on the notion of internalised oppression, the author argues that the complexity involved in being affected beyond the original traumatic event should help make our understanding of the impact of traumatic events at a different level.

Based on Giddens Structuration theory, it will have to be acknowledged that the proposed policy and practice changes may require long term political and economic changes. This will require policy makers and scholars to fully examine and establish the structural forces involved and which requires to be modified so as to engender the required improvements in the lives of PWLD. Resistance to change can be a major problem at society and social group level that it can be even difficult to getting more PWLD involved in processes that are aimed at improving their lives. This can be the case is when considering the factors such as internalised oppression and power relations. Hence, strategies should be in place to address these barriers within the society's systems. Thus, a step by step and evidence-based approach to introducing, managing and reviewing changes affecting PWLD may be useful.

SUGGESTIONS FOR FURTHER RESEARCH:

Evidence from literature suggests that the implementation of the policies aimed at reducing the oppression of PWLD is generally not evidence-based and literature on this subject is mainly expert opinion. According to Cummins and Lau (2003) such policies as community integration or inclusion tend to be presented in the literature as straight forward processes with little or no sound critical analysis of the problems involved to achieve this. Sharing similar views, Lister (2007) points out an evidence-based approach is necessary considering that the mainstream community where PWLD are being integrated already has powerful exclusionary structures and is choked with

layers of other inequalities. The author argues that there is scarce literature that details how this unwelcoming mainstream community and the socially powerless PWLD can come together to integrate. The various factors that influence their marginalisation and victimisation such as age, gender, level of disability, challenging behaviours of PWLD and society's attitudes towards PWLD are thinly explored, and also there is very little in terms of solutions to overcome the highlighted problems (Winkler et al. 2006). Without robust empirical studies which consider all complexities involved, the efforts to develop and implement policies effectively will remain inadequately informed and this can only help to prolong the oppressive experiences affecting PWLD (Cummins and Lau 2003; Lister 2007).

The findings and implications of this study highlight some avenues for future research. These can be framed around the following 3 topics: Addressing the limitations of the study, Building on research findings and New research avenues.

Addressing the limitations of the study:

A limitation of this study was the opportunistic sampling due to the recruitment difficulties encountered. Although the opportunistic sampling provided the selection of information-rich cases, the sampling technique introduced biases such as under-selecting female participants with LD, over-selecting white male participants and missing PWLD from ethnic minorities. Future studies can attempt to use a sampling technique such as maximum variation sampling that can address this issue of lack of heterogeneity. Maximum variation sample facilitates the maximisation of the diversity of the study sample including level of disabilities, age, ethnicity, settings, occupation and marital status (Patton 1990). In turn, this may help to provide the wide spectrum of life experiences and opinions, thus, with the potential to capture data not generated in this study.

Building on research findings:

This study has explored and attempted to understand social problems affecting PWLD in terms of oppression. The literature reviewed showed that only a few studies on PWLD looked at oppression as their primary focus. Considering the scarcity of studies in this area, the general suggestion is that more studies are still needed to develop deeper insight and better understanding of the bigger picture of the social problems PWLD face.

Building on the research findings of this study, specific lines for further inquiry have been identified. Based on the evidence that the marginalisation and victimisation of PWLD have continued to persist unabated, further studies will be necessary to examine in-depth the factors helping to create and sustain the existence of these forms of oppression. This should help to develop a greater understanding of the role of society or social structures in imposing barriers that restrict social, political and economic participation of PWLD.

Still on the issue of causes of oppression, a specific focus can be directed to the problem of society's negative attitudes. The evidence in this study identifies this as the single major cause of the oppressive experiences PWLD face. The literature has shown that little is being done to tackle this problem directly. Hence, there is need for further studies on this topic area. This will be essential to raise awareness on how the negative attitudes develop and become the nuclei from which society's behaviours are derived. Importantly, it will be crucial to help develop achievable policy strategies specifically aimed at reducing these negative attitudes.

Another area, which may require further exploration, is the extent to which practitioners and care services have continued to control the lives of PWLD. An entire industry has arisen around the perceived needs of PWLD. Questions will have to be asked about who benefits from this controlling relationship and whether it is possible to break the cycle of this relationship without jeopardising the lives of PWLD.

New avenues of research:

As this study shows, the greatest challenge of all is to socially include this group by recognising and valuing PWLD as having a meaningful place in human social relations. Hence, bold steps have to be taken to focus on investigating how best technology can be used to help society organise work differently in a way that can accommodate PWLD and people with other disabilities.

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APPENDIX

APPENDIX 01: INFORMATION SHEET FOR PEOPLE WITH LEARNING DISABILITIES



INFORMATION SHEET

This item
has been
removed

due to 3rd **Research Project: Experiences of Victimisation amongst People with Learning Disabilities**

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be found in the Lancaster Library, Coventry University.

My name is Denford Jeyacheya. I am a research student at Coventry University. I am also a nurse for People with Learning Disabilities.

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I am doing a research project for my course. I am inviting you to take part in this research project.

Before you make a decision please read the information below. Feel free to ask me any questions. You can talk about this information with your family and keyworkers.

What is the research project about?

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I would like to hear about your experiences of being bullied or hurt by other people.

This could be things like:

Calling you names

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Spitting at you

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Pushing you

Hurting you

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It could be something else not mentioned above. You can write this in space below:

I would like to find out:

- 1. In what way you have been bullied or hurt by other people**
- 2. Why you think people bully or hurt you**
- 3. What you do to try to stop people bullying or hurting you**
- 4. What you feel and think about being bullied or hurt by other people**

Do I have to take part?

You can say no if you do not want to take part in the research. Saying no will not affect the care you receive in any way.

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What do I have to do in the project?

You will answer questions about your experiences of being bullied or hurt by other people. You can only talk about what you feel comfortable talking about. You can only talk about those really bad things that have happened if you have already reported them to someone like a support worker or the police. Our talk would be private and should be about 45 minutes long.

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If you do not mind I would like to use a tape recorder to record the interview. I will not tell anyone about what you say and when I have

listened to the tape I will delete it. I can give you a copy of the interview on tape if you would like one.

Also, if you want some to be present and help you talk about your experiences, this is okay too.

What may happen during our talk?

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The unabridged version of the thesis can be found in the Lancaster Library, Coventry University. **If you feel that you are getting upset during our talk, we can stop for a break. Remember you do not have to answer any questions which might make you to get upset.**

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Also feel free to stop the interview at any time. You do not have to give a reason for stopping.

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You can ask for support from your keyworker.

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Where the distress has to do with your experiences of being bullied or hurt by others, you can request for more help from these organisations:

VOICE UK: Rooms 100-106, Kelvin House, RTC Business Centre, London Road, Derby DE24 8UP

RESPOND: 3rd Floor, 24-32 Stephenson Way, London, NW1 2HD

How will this research help me?

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be found in the Lancaster Library, Coventry University.

This research may help to find ways of stopping people from bullying or hurting people with learning disabilities.

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The police, the government and support workers may use this information to help you. I will also give you a summary of the results of the project if you would like a copy

How your privacy and confidentiality will be maintained?

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All information we share will be kept safe in locked cupboards and rooms.

All the information will be destroyed at the end of the project.

Information will not be kept confidential where a person's life is in serious danger.

If I want to participate:

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If you agree to take part, you will be asked to sign a consent form enclosed with this information sheet.

Who do I contact if I have any comments or questions about the study?

Feel free to contact Denford Jeyacheya

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due to 3rd
by email Party jeached@uni.coventry.ac.uk
Copyright.
The
unabridged
version of
the thesis
by phone can be **07898604385**
found in the
Lancaster
Library,
Coventry
University.

by post **RC 42 , Coventry University, Priory Street,**
Coventry, CV1 5FB

Thank you for taking the time to read this letter and for your help.

Yours sincerely


Denford Jeyacheya

APPENDIX 02: CONSENT FORM FOR PEOPLE WITH LEARNING DISABILITIES

Title of the Project:

An Eploration of the Oppressive Experiences Affecting People with Learning Disabilities

This form is so that you can tell me you are happy to take part.
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Please put a  in the YES OR NO box to all questions and sign at the bottom.

	This item has been removed YES	This item has been removed due to 3rd NO
1. I understand the information about the research project. I have had the opportunity to think about the information and to ask questions.		
2. I understand that taking part is entirely voluntary and that I am free to change my mind and withdraw at any time, without giving any reason.		
3. I agree to being interviewed and the interview being tape recorded.		
4. I agree that (anonymous) quotes from my interview may be used in the write up of the study and may be published.		
5. I would like to receive a summary of the results.		

6. I agree to take part in this study.		
--	--	--

Your name

Date

Your Signature

Researcher Name

Date

Researcher Signature

Witness:

Date:

Witness Signature:

APPENDIX 03: INFORMATION SHEET FOR PRACTITIONERS

Title of Study:

An Exploration of the Oppressive Experiences Affecting People with Learning Disabilities

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to 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 others if you wish. Ask us if there is anything that is not clear or if you wish to know more. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

What is the purpose of the study?

The specific aim of this research project is to gain a better understanding of a) the types of oppression people with learning disabilities (PWLD) face; b) the likely causes of victimisation; c) support received from the police and others in cases of reported oppression; and d) the impact that oppression has on people's quality of life. The goal is to help raise awareness of the difficulties faced by PWLD and to develop a series of policy initiatives that can be introduced in order to help identify and prevent repeat victimisation.

Why have I been chosen to take part?

You have been identified as a potential participant for this study as you are a person who provides care to, advocates for or supports PWLD in any community setting.

What are the benefits for you of taking part?

There are no direct benefits of participating, however we believe that by participating and allowing us to conduct this study, you will contribute to the greater good by providing real data regarding victimisation experiences amongst PWLD from which awareness of these problems can be raised and policies can be derived.

Do I have to take part?

We emphasise that participation is voluntary and that participants are free to withdraw at any time without giving an explanation. Withdrawing from participation will not disadvantage you in any way.

What will happen if I take part?

If you agree to participate you will be asked to complete an interview which will take about 1 hour. The interview will include questions regarding a range of victimisation experiences amongst PWLD. We will be interested in how these victimisation experiences affect the quality of life of PWLD, the strategies PWLD adapt and the support given by others help to prevent further victimisation and in what you consider as the major causes of victimisation in this client group. We will also ask for your opinion on what you think should be the way forward in tackling the problem of victimisation amongst PWLD.

What are the risks?

There are no major risks expected in your taking part in this study. However, discussing personal experiences may be potentially upsetting. Therefore, if you feel uncomfortable with any of the questions you do not have to answer them. If you want to stop the interview you can do so at any time without giving us any reason.

Is Confidentiality guaranteed?

We take confidentiality very seriously. All personal information about you is regarded as strictly confidential. Only the researcher asking these questions and the study supervisor will be able to trace the information you have given us to your personal details. All the information about you will be coded; you will not be identifiable in any research outcome (e.g. publication). This ensures that suitable standards of security and confidentiality are applied. All information collected will be securely held in Coventry University. Only in cases where you tell us something which may place you and others at severe risk would we consider breaching confidentiality. In those cases you might be contacted by an expert from the study team.

What is something goes wrong?

Should something go wrong or if the study has harmed you in any way, it is essential that you inform the researcher of this study as soon as possible and will try to provide help.

What will happen to the results of the study?

The results and findings of the study will form part of a report that will be given to Coventry University as part of the researcher's final dissertation. Results can also be published in journals. On completion of the study all data will be destroyed. You will receive a summary of the results if you are happy for this to be done. You will not be identifiable from the results unless you have consented to being so.

What will happen if I want to stop taking part?

If you want to stop taking part, results up to the period of withdrawal may be used, if you are happy for this to be done. Otherwise you may request that they are destroyed and no further use is made of them.

Who is funding the project?

The study is being organised by the Principal investigator and funded by Coventry University.

Who has reviewed the study?

The project supervisory team at Coventry University and the Coventry University Ethics Committee have reviewed this research study.

Who should I contact for further information or to comment on the study?

For further information or to comment on the study, please contact the principal investigator: Denford Jeyacheya at this address: Faculty of Health & Life Sciences, Richard Crossman Building, Priory Street, Coventry, CV1 5FB: Tel- 07898604385, Email: jeyached@uni.coventry.ac.uk

Research Supervisor: Dr Anthony Colombo at this address: Faculty of Health & Life Sciences, Richard Crossman Building, Priory Street, Coventry, CV1 5FB. Tel: 02476795819, Email: acolombo@coventry.ac.uk

Thank you very much for your time and once again please ask for more information on the project if you wish.

APPENDIX 04: CONSENT FORM FOR PRACTITIONERS

Title of Project:

An Exploration of Oppressive Experiences Affecting People with Learning Disabilities

- 1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason
- 3. I understand that all the information I provide will be treated in confidence
- 4. I understand that I also have the right to change my mind about participating in the study for a short period after the study has concluded
- 5. I agree to be filmed/recorded (delete as appropriate) and for anonymised quotes to be used as part of the research project
- 6. I agree to take part in the research project

Name of participant:

Signature of participant:

Date:

Name of Researcher:

Signature of researcher:

Date:

APPENDIX 05: ETHICS APPROVAL

REGISTRY RESEARCH UNIT

ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Denford Jeyacheya **Faculty/School/Department:**
HLS.....

Research project title: Research Project: Experiences of Victimisation amongst People with Learning Disabilities

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

On the information provided to me, Denford has give due consideration to the ethical circumstances that interviewing learning disabled participants entail.

2. Evaluation of the participant information sheet and consent form:

Overall the participant information sheet and consent form are good, but I think the information sheet needs a little more attention. Under what is the research about, I would break this down more and in a larger font size. A general description of what bullying is understood to be might help. Give some written examples of bullying to marry up with the pictorial information and the space for the participant to identify examples of their own. Then ask the four subsequent questions. Depending on how you are intending to recruit participants, you may not know the literacy ability of the volunteers until you go through the information form- so a larger font size is needed.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

- Approved - no conditions attached
- Approved with minor conditions (no need to resubmit)
- Conditional upon the following – please use additional sheets if necessary (please re-submit application)
- Rejected for the following reason(s) – please use other side if necessary
- Further advice/notes - please use other side if necessary

Name of reviewer: Martin Bollard.....

Signature:

Date: 0707.11.....

APPENDIX 06: INTERVIEW GUIDE FOR PWLD

PART ONE: BACKGROUND CONTEXT

Interviewer comment: Our discussion will start by asking you a few questions about you in general such as your age and general state of health

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01) Are you providing information about you or someone else?

You
Someone else

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02) If you are providing information for someone else, then who

Are you?
Relative/family member
Carer
Friend
Support worker
Other, please specify

03a) Socio-demographics

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03) Please tell me about yourself (or the person that you care You)

Age:

Gender:

Marital Status ... history

Ethnicity:

Religion:

Sexual orientation:

Schooling ... history/qualifications

Where do you live ... accommodation history

What do you do during the day ... work history

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03b) Physical health related difficulties

Use a wheelchair

Have difficulty walk

Are blind or visually impaired

Are deaf or hard of hearing

Have speech difficulties

Have less obvious difficulties (such as autism, diabetes, epilepsy, anorexia)

Have a long-term illness or health condition (such as cancer, HIV, diabetes)

Other difficulties, please specify

How often did you spend time in hospital/care settings due to these difficulties?

03c) Cognitive related difficulties

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Have learning difficulties, if yes:

IQ level

Main problems

How often have you spent time in hospital due to these difficulties?

Have mental health difficulties, if yes:

Do you have a psychiatric diagnosis? History

What are the key symptoms/problems you have experienced?

When was the worst time for you? What happened?

How often have you spent time in hospital due to these difficulties?

03d) Childhood difficulties – Within family

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What were things like for you as a child?

Generally happy or unhappy childhood

Relationship with your parents/siblings,

Traumas (death, divorce, separation, domestic violence)

How were you treated as a child?

Cared for Punished

Given encouragement

03e) Childhood difficulties – Within school

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What were things like for you at school?

Did you have many friends?

Did you ever get into fights? Why?

Did other children pick on you, you pick on them?

Why?

Would you say that you were bullied – history frequency, nature, etc)

03f) Social issues:

What do you most like spending time doing:

Spending time going out socialising with my family

Spending time going out socialising with my friends

Spending time going out and meeting new people

Spending time at the day centre/place of work

Spending time at home on my own

Spending time at home with my family or friends

What are your favourite hobbies/interests – things that you like to do the most?

PART TWO: EXPERIENCES OF VICTIMISATION

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04) Have you ever been bullied or hurt by another person?

04a) If yes, can you tell me roughly how often this has happened to you during the last year or so:

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Almost every day
At least once or twice a week
At least once or twice a month
At least once or twice during the past year

04b) Can you recall the most serious incident in which you were bullied or hurt by another person during the past year or so? What happened?

For each incident, use the following markers:

Relate first to the specific incident being discussed and then more general – is this what frequently happens:

Form: saying nasty things about you (verbal abuse, phone calls)

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Spitting at you; throwing things at you. Writing nasty things
Writing nasty things about you (letters, texts, graffiti)

Physically hurting you (kicking, hitting, pushing)
Threatening to hurt you; Making unwelcome sexual advances (touching, pestering,

Repeatedly picking on you/pestering you (harassment)
Stealing something from you (money, property)

**Damaged something of yours (property, home, garden)
Other, please specify:**

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Who was involved:

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Children – teenager

Partner, Friend, neighbour, carer – stranger

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Relative/family member, Adults, Male or Female

**Group of people or individual
Other person with mental health problems**

Where:

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Private space (your home, garden, other person's home)

Public transport (bus, train, taxi)

Public space: (park, street, shopping centre)

Public premises (pub, cafe, place of work, day centre)

Time of the day:

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: Morning, afternoon, evening

PART THREE: QUALITY OF LIFE

Expression: What words/phrases best describe how you felt after this happened

**Upset, angry, unhappy, sad, terrified, frightened, devastated,
Shocked, the worst day of my life,**

How satisfied are you with

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**Your comforts (housing, food, clothes, heat, etc)
The neighbourhood community in which you live
Your opportunities for leisure activities or hobbies**

**Your relationships with family
Your friendships
The way other people treat/respect/behave towards you
with life in general**

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be found in the Lancaster Library, Coventry University.

Your physical health
The level of community mental health support you receive
Your social life (clubs you belong to and activities involved in)

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04d) Anxiety: How worried are you about being bullied or hurt by other people in the future? Scale 1 to 10.

PART FOUR: PREVENTION STRATEGIES

Self prevention: Did you try to stop the person?

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If yes, how did you try and stop them?

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Carry weapons and personal alarm
Avoid going out at certain times of the day
Avoid going to certain places
Avoid talking to people who hurt/frighten me

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Stopped going out

Denford Z. Jeyacheya 3079452
This item has been removed due to
3rd Party Copyright. The unabridged
version of the thesis can be found in
the Lancaster Library, Coventry
University.

Move house
Change jobs
Changed phone number
Other solution, please specify

Did it work, if not, what happened?

Formal prevention: Have you ever reported this/these incidents to the police?

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Copyright. The unabridged version of the
thesis can be found in the Lancaster Library,
Coventry University.

If yes, what did the police do?
Took down details, but took no further action
Stopped the person from hurting me
Told me they could do nothing
Where you happy with the police response?

If no, why didn't you report this/these incidents to the police?

Other prevention: Have you told anyone else about this/these incidents?

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Party Copyright. The unabridged version
of the thesis can be found in the
Lancaster Library, Coventry University.

If yes, who: Relative/family member
Friend
Neighbour
Carer or other professional

If no, why haven't you told anyone else about this/these incidents?

It was not important enough to tell anyone

I have a relationship with person who hurt/frightened me
No confidence that anyone can help
Embarrassed
Difficult to explain what happened

**It is just part of 'everyday' life
It happens too often to report
Don't want to be a bother to people
No one can really help stop it**

PART FIVE: CAUSES OF VICTIMISATION

05) Why do you think that other people wish to hurt / frighten you in these ways?

Situational factors:

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**Where I live – unsafe neighbourhood
People I hang around with
Places I go
Things I get involved in**

Personal factors:

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**Mental health
Other disability
My religion / sexuality
My attitude / own stupid fault / just bad luck
Other, please specify**

Social factors:

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**The amount I drink
The drugs scene I belong to
My involvement in crime**

APPENDIX 07: INTERVIEW GUIDE FOR PRACTITIONERS

PART ONE: INTRODUCTION, BACKGROUND & CONTEXT

Introduce yourself then:

- Give a background to the project- aims and objectives of project, interviews with people learning disabilities and a small number of professionals and carers
- Explain the structure of the interview

May start by asking question:

- First of all, could you tell me a bit about your role and how it relates to victimisation experiences of people with learning disabilities.

Note the following

- Gender
- Occupation & role
- Experience of working with PWLD
- Type of PWLD they work with

PART TWO: PWLD EXPERIENCES OF VICTIMISATION

Ask for the nature of crime committed against PWLD in their care, Details of what happened, characteristics of perpetrator , where and time of the day this happened, the person's reaction to the incident

You can ask these questions:

Based on your experience of working with PWLD, can you describe examples of criminal victimisation experienced by the clients you work with or have worked with.

For each example probe for the following:

What actually happened?

Who was the perpetrator? their gender, adult or child, with learning disability or not

Where did the incident take place?

At what time of day did this happen?

What was the person's reaction to this incident? Their thoughts, emotions and behaviours

What are your feelings and thoughts about these victimisation experiences?

What do you think are your main views about victimisation experiences amongst PWLD in general?

Find out if the participant has something else to add, then move on to part three

PART THREE: THE QUALITY OF LIFE OF PWLD

- a) Ask for opinion about the QOL amongst PWLD in general
- b) Ask for how experiences of victimisation affected or affect the quality of life of PWLD in their care and in general.

You can ask these questions:

Part a:

How would you describe the quality of people with learning disabilities you provide care to. Also ask for a general opinion.

How good? How bad? How acceptable/unacceptable? Positives and negatives? And why good/bad/acceptable/unacceptable/positive/negative?

Part b:

After the experience(s) of victimisation mentioned, what changes, if any, did you or other members of the care team noticed.

Probe to find out whether changes were noticed in the following areas:

Behaviour

Emotions (anger, irritability, unhappiness

Mental health (mood swings, anxiety, flashbacks, aggression, hearing voices

Physical health

Relationships

Accommodation arrangements

Lifestyle

Daily routines

Travelling

Find out whether there are other changes noticed in areas not listed above.

What support do you (organisation) provide to help maintain or improve victims' quality of life?

Has the support helped/ is it helping? And in what way?

In general, how else is the quality of life of victims of crime with LD can be affected?

Find out whether there is something else the participant would like to add before moving on to part four

PART FOUR: PREVENTION STRATEGIES

Ask about the measures PWLD take to prevent repeat or further victimisation, the help they seek from others. **These will include how people have restructured their lives: moved home, spending money on security of their homes, self-defence training, in possession of weapons when travelling or at home, changing travelling routes and times, using taxis for travelling, being in the company of others all the time, getting help from social services, professionals and police,**

You can ask these questions:

What strategies have you or other care team members observed PWLD adapting to cope with the victimisation?

Do these strategies work? Justify any answer given

How do you, as the care team, support the victims to minimise or prevent further victimisation?

Does this support help to reduce or prevent further victimisation?

What other help is available? And is this being used? If not why?

Find out whether the participant has something to add before moving to part five

PART FIVE: CAUSES OF VICTIMISATION

Ask for the possible reasons or explanations of why PWLD the participant has worked with were targets of victimisation

You can ask these questions:

What do you think are the likely reasons/explanations of why the PWLD you mentioned/ talked about were victimised?

Healthcare worker to justify each reason and further probes may be required where people generalised statements such as

Having a learning disability (how does this make them more vulnerable?)

Communication problems (In what way?)

Cognitive impairment (can you expand a bit on this?)

Dependency on others (How does this increase vulnerability)

Poor social skills (how?)

Geographical location, social status, low levels of education, Quality of life

In your own opinion are there any other reasons for why PWLD are vulnerable to victimisation in general?

What do you think should be the way forward in dealing with the issue of victimisation of this vulnerable group?

APPENDIX 08: INTERVIEW TRANSCRIPT ANALYSIS

Transcript PWLD 02:

Male, Mild LD, Attended special school, Parent and is Working

Background Information:

Not said on the tape: Client's wish for this information not to be recorded but happy for the information to be used:- Interviewee Stated that his victimisation started at home. He was seen as someone different from the start and felt his daddy never liked him. He was the first born and was not the 'perfect child' dad expected. He believes his dad liked other children more than he did to him and never treated him fairly. He feels if his daddy did not and does not like him who else is supposed to like him- "I can forgive everybody else for treating me unfairly but not my father". (To remind interviewee to talk about employment experiences and experiences with the social services)

Taped recording started here:

PWLD answer 2: I have never been seen as someone who could be successful in life. My dad told me I could never have a good job, never have kids of my own and I will never live on my own. And I proved him wrong. The fun thing at the moment is that he is not working and I am. But because he sees me as someone from abroad and I have my comfort back on now. But because of my daddy I suffered for a long time (victimisation by dad)

Denford: so that is the first thing there to do with your dad. You felt he never liked you because you have a LD and you expected you as the first born to be a 'perfect child' and that did not happen that way. So as grew up what else happened?

PWLD answer 2: I went to a special school. I did not do much there and it was just a waste of time. My mum never wanted me to go to a special school but she had no other option. I found out that I was dyslexic too apart from having a LD. (Attending special school) this is a waste of time. I was angry about it, quite bitter. (Issues with SEN schools)

Denford: From the beginning it was from dad and then going to a special school (which you did not want). What about in your adulthood?

PWLD answer 2: Its was my first partner (with mild LD too)with whom I have kids. She used to the mick out of me and used to steal my money- taking the mick out of me a lot and . bank card. She went to a special school like me and I know she had LD like me but she took advantage of me it.

Denford: What about the way other people in the community treated you?

PWLD answer 2: Here I kept myself to myself really. I did not mix with other people. At that time my confidence was not good and was scared to talk to people and now I have lot of friends now.

Denford: What were you scared of?

PWLD answer 2: I was scared of what people could do to me, that people could take advantage of me. I felt really vulnerable (fear, lack of trust of the public, lack of confidence-they will take advantage of my weakness associated with having a LD and my low self-esteem and fear people would cause harm)

Denford: As a parent now, do you believe you have been unfairly treated in any way?

PWLD answer 2: Funny enough now. My ex-partner respects me now. But I will never trust her again. But I have a good relationship with my 3 kids. My two year old listen to me but at two they are closer to their mother. I feel happy about that. I feel like a proper daddy now.

Denford: That's good news if that's how you feel now.

PWLD answer 2: I felt like my ex-partner used to have a lot of power. She always got her own way. She did not want me to see my kids. I feel like I have missed a lot. My ex-partner, I don't know how to say it. She always wanted to get her own way, getting me angry and stopping me from seeing the kids. It is not fair. I had to back down a lot keep the peace

Denford: You said you wanted to say something about employment?

PWLD answer 2: Yah, yah. I had a couple of jobs before I got the job I have at the moment. The first job I got when I was 20/21years old, it is a long time back. I forgot the name of the place because they keep changing the name, at times people patronised me, taking the mick out of me, putting me down a bit. Then I got another job later (at a warehouse). That was the worst job I have ever had, how I worked there for six years I don't know? People got me a job at the college. It was fine at first and then things started to change. Because I wanted to better my -self (professionally develop) so that I could challenge myself on these jobs. They understood that but it never happened (never given the opportunity to professionally develop or progress). I had to do a lot of over-time job I never wanted to do and did kind s of jobs no one else wanted to do like dusting, - they were boring, they will take me down repeating the same boring work everyday. Because I wanted to stay, I told the managers but nothing was done- I think they were just patronising me because nothing was done. I could have packed the job in (left the job) but I did not. Iif I had done that I could have lost the benefits. The bullying started, it was abuse- they used to call me names. I put up with it for

a bit. I told them to stop calling me names but they would tell me they were just joking. But it is not a joke. I then complained about it and nothing got done like usual. Then it was other verbal abuse and then it got to physical abuse- throwing shoes at me, hitting me and I could have packed my job in (left) but I had to put up with it. I was doing a job I did not want to do, putting me down, I was depressed and having to be abused for three days a week. I was there three days a week and how I stayed there for six I don't know.

Denford: So it was an on-going thing?

PWLD answer 2: It was not only on-going. They did not have LD and put a PWLD to work in a warehouse, I thought that was horrible. I did not want to fight back because I could lose have lost my job. I had to put with it for six years. My confidence went down, I felt really depressed , I would lash out a lot (at other people not involved in abusing me) and felt more isolated a lot more then. I was scared of people.

Denford: It was not good experience. You also wanted to say a bit about the way you have treated by the social services?

PWLD answer 2: It all started with the mid-wives and then the social services. I thought they were quite patronising. I wanted to look after my first child, my son. It got me annoyed by my partner and I was left in the cold- denied permission to look after my child and not allowed time to spent time with my child. I wanted to look after my child with my partner if she had no time. I needed to look after him at the weekend to give her a break. It takes two to make a child (laughs. But I think I have got a right to look after my child. I found this odd. It is nowadays and it is not in the 1950s or 1990s. When I argued about it I was kicked out of the meetings. I was simply debating about it and they did not like it. Because I was just speaking my mind. I don't know what I should have done to – my partner, sometimes she put me down a little bit telling me to just leave it. Why do I have to leave it, I have to look after my son. I want to be there too. I thought children were there for mums and dads and not just for mums. (It takes two to have a child and the child will benefit from both mum and dad). They cannot just face it. (Does not understand why he was not allowed access to his child- child only looked after by mother with a LD too- with Social service support).

Denford: Do you think there are PWLD out there who are being treated unfairly?

A: It depends on where people are living. If you are living in a run -down area the chances to bullied and abused are a lot higher. Where I live myself, I live in a network called X (name given) link for PWLD. Before I moved to X myself, the area I used to live was a bit doggy. I was bit scared, they called us names- retards and what have you. But where I live now, I am not getting none of that.

Denford: Where you live, is it a support living accommodation or what?

PWLD answer 2: What is all about, xx- you are part of network, you got living – a volunteer part worker and is living near your house about 10-15 minutes where you live. If you just moved into place X network, they have to get the part worker in the beginning and when you are more confident and more experienced living on your own, the part worker go down. Because they wan t

you to live more independently and be part of the community. But things have to be worked in your own terms. If you got any trouble in the network, we have meetings where you can discuss them. If you have tenants in the network bitering or arguing we have a meeting to sort things out. If it does not work out it goes to the complaint panel I think. But things in place x are good and makes you feel confident . Most of the tenants tell me that when they used to live in run down areas they were bullied a lot , targeted and bullied a lot and everything. Not the same now.

Denford: When you say bullied at what exactly will be happening to them?

PWLD answer 2: Bullied in many ways, physical- hitting, name calling, verbal abuse. And people pretend to be your friend, I don't know whether you have heard about this, people pretend to be friends to PWLD but they are not- they take their money and that happens too (MATE CRIME)

Denford: In your opinion, what time of the day does this bullying usually happens.

PWLD answer 2: It depends. These things, it happens 24hrs a day don't they. It depends on where you are living, where you work, if you got partners or not. (So it is any time of the day depending on individual situations/circumstances)

Denford: Where it happens- so you are saying it can happen at work, at home where you live)

PWLD answer 2: Yes, at home, at work, and it can happen on the street. Where I live, you have got these kids who bully you because you got a LD. When I was younger, I used to get a but to school- kids used to call me retard and so many other things like that. We used to go a school in a school bus where they called me all sorts of names- I hated that bus and just wanted to go on my own but they would not allow us to that.

Denford: In the past 10 or 15 years, do you think things are better or getting worse?

PWLD answer 2: I did not think about that. It depends on where you are living. (in some places it is getting better and in others it is getting worse). I know where I live it is getting better. But for other people living independently is likely to get worse because of the cut backs (by government-funding reduced and support reduced)

Denford: Ok. Do you have anything else to about your experiences other people's experiences of bullying/unfair treatment?

PWLD answer 2: I would like to move to next question please

3. Quality of life?

Denford: What can you say about your quality of life:

PWLD answer 2: It is good

Denford: In what way is it good?

PWLD answer 2: Right now I can fight for myself, I fight for PWLD and feel proud about it. I feel I have a lot more confidence now compared to when I was 10 years ago. I was quite timid frightened of people 10years ago. I happy with where I live, what I own. I feel I am not isolated, I feel I am

part of the community, I feel I have got a good job, feel professionals respect me, I speak out for PWLD. I feel I am outspoken now- I was never outspoken 10 – 15 years ago. All I wanted was a quiet life and did not want to get into trouble speaking up.

Denford: So you feel the community has accepted you?

A: Yah, I feel accepted. I get along with these people with the chip shop, I have good friends (without LD- made friend outside the LD community). Feel they respect me. But where I lived before that I had none of that- no communication with neighbours (and no friends outside LD network)

I forget to tell you about something. when I lived at place X (supported living accommodation. My brother moved in with me. Living on my own , I could not pay my bills right, properly for myself. My brother (younger brother) moved in. It was intended that he helps/supports me to pay my bills because I was not able to do that at the time. But in the end my brother took over. He got it from my dad and he would do everything for me but I needed to do it on my own (with support at first). He just thought I will do it wrong if he had let me do it on my own. He did not have the confidence to trust me and I got over-powered. When I went to join advocacy group X , I did not need all that. I wanted to know how could look after myself properly and to do other skills -to do me cooking, pay my bills and to be confident living independently. My brother would not have none of that. I cannot say he bullied me but he sort of over-protected me (**OVER_PROTECTION, did not understand brother's intention at the beginning saw it as bullying. Did not like the over-protection and taking away of his independence, creation of dependence but realised that brother did that with the intention to help and not to bully him- however it caused a lot of distress.**). He is lot better now but now and again he slips into it. He is my younger brother, he felt he has the obligation to look after me but I did not need it. My mother told him about it. All he does now is ask me if had paid my bills and I tell him yes. The only time I asked him for money was when my money was stolen by my ex-partner and another woman.

Denford: How did all this victimisation (bullying, harassment, over-protection etc) affect your quality of your life?

PWLD answer 2: At the beginning it was very hard, very very hard. I felt very isolated, I felt quite depressed a lot, at one point I thought of ending it (suicidal ideations). I could not take the bullying at work, with all the bullying by my brother, I could have taken my own life. It was too hard. Now I can say it is a lot better but I cannot say I have got over it yet because I can still get depressed sometimes (on and off)- **Long term effect**. Now and again the depression comes, it came again last year when I got into trouble at little bit at work with my co-worker (being patronised and people trying to put me down). But it got sorted out at the end. I reported her and she is left. My depression came up quite a few times. What happened is that she used to come to work late and I was there early on time. This means I had to do a lot of work and she used to put me down. Whatever good work I did she never noticed it (**some form of exploitation**). She got told to leave. But the co-workers after her they were all good. But I did not want to say anything to get her in trouble, I do not like grassing people but I had no choice then because a woman with learning disabilities

reported it for me/ spoke out for me because at that time I was getting really depressed and really down. I did not want to report it but other people with LD noticed it and reported it for me. Last year was a bit down because of personal issues. My ex-partner wont allow me to see my child. That made me feel very low.

Denford: How do you try stop or prevent people bullying or treating you unfairly?

PWLD answer 2: I now confident to do it now. When I notice people being bullied now I step in so that spell it out. Because where we work we do a project about hate crime. That helped me to be aware about bullying. One of my friends I know has been bullied. He did not tell me at first but he did tell me at the end that he was being bullied by his next-door neighbour. She used take a lot of money out of him, making a lot of noises and he could not sleep. He was scared if had told council, he would get into trouble. But I encouraged him to tell council and I had to accompany him to put a complain. She (the victimiser) did that with her previous neighbour who moved out because of the noise. This time she got into trouble for it for bullying him. But I feel proud for helping him and to give the confidence to take it to the council.

Denford: Any other examples of how people deal with being bullied?

PWLD answer 2: I think PWLD, I think they need to be more confident to, if they are being bullied, abused, verbally and physically abused, to take it to the advocacy or talk about it to another person with LD. He or she need to back them up.

Denford: Why not report to the police then?

PWLD answer 2: Funny enough I am not a big fan of the police. When I got whapped/mugged, I did not feel I knew how to report to the police. Because I thought they are quite patronising . My mother went with me to the police and what happened- I thought they were talking to me like I was the criminal. I felt really down and got my mother upset. She told them there is no need to speak to my son like that. He has not done anything wrong. The people who mugged him did something wrong. Because of that I will never go back to the police. I know where I am working they are doing some training with the police. But myself, I do not have any faith in them. It will need a lot to convince me that they have changed. Useful quotation

Denford: So you can report to advocacy group, at work,

PWLD answer 2: and also to the Council and to my parents. Not to the police. I got mugged twice but did not get any help from them.

Denford: Do you think PWLD are getting help to deal with all this victimisation- bullying, harassment, unfair treatment?

PWLD answer 2: It depends on where you live. If you live in run down area you are likely to get less or no support. Those in supported living accommodation are likely to get more support. Those who work with advocacy groups get a lot of support. Advocacy group members get bullied a lot less now.

Denford: So you are saying it helps to be part of LD group/organisation, and to get the support of other people with LD

PWLD answer 2: Yes and the support of people without LD too. A good mixture of PWLD and without LD does help.

Denford: So what do you think need to change then for PWLD to get this support?

PWLD answer 2: I think we need to do a lot more of awareness training (in which he is involved). Getting PWLD to be part of the community more and not being isolated. Not just that, there is another issue too. Where we work and what my advocacy group does, we do a lot of training with parents with LD. A lot of social workers need to be aware about how they treat parent with LD. I think they are quite patronising, parents with LD have no say, they always pick on things they cannot do and not on what they can do. It will be helpful for them to come up with training programmes to help parents with LD. I does not mean we are not good parents. I am not saying all social workers are bad apples. There are some who want things to work better . But for things to get better parents with LD will need training to look after kids and not for them to be in the care of social workers and doctors (**Role of the State through social services & doctors**) .

Denford: So you are saying awareness is important not just to PWLD but also the community and professionals

PWLD answer 2: Yes , professionals and everybody. That it makes it easier for the needs of PWLD to be accommodated. Another thing, when PWLD move to new homes it can be difficult for them. What we need is housing training before you live independently- this include how to pay your bills, cooking, tidying your house and all you need to do (and perhaps likelihood of exploitation and bullying or being victimised). I know people who had moved from institutions, they were two days from institutions, and they moved to live independently on their own. It was just too soon and I believe the two guys needed training before they could live more independently.

Denford: Do you have anything else to say about your quality of or of PWLD in general?

PWLD answer 2: I think I have said all I can say

Denford: I will move on to the last part of the interview

PWLD answer 2: That is Ok

5. Causes of Learning Disabilities:

Denford: What do you think make PWLD get bullied or ill-treated?

PWLD answer 2: I think People's attitude. If you have a LD and if don't they know you, they automatically pick on you- they call you names and do all sorts of things to you. Because they don't know you. **Because you have been to a special school, you are not one of them and that is not fair. I think we need to, if I was the Government, I will shut down all the special schools and mix everyone in the main schools. That's where the problem is – we are isolated from the start and we stand out when we mix with them because they don't know us. They are from special schools- they separate us, box us up like things. We feel we are separate and that needs to change. The best thing**

to do to change the attitude is to get PWLD with mild and moderate LD to be normal school schools and it can be done. Because it happened with my son. They wanted to take him to a special school. Me and my partner (we were together at that time) we had to fight for him to stay in the main school. We stood our ground and told them if he went to a special school it will go down- hill. I did not want him to experience what happened to me. They got him to smaller classes, he also gets 1:1 teaching lessons. That could happen to many PWLD in normal schools instead of taking people to special schools all the time.

Denford: Do you think it is all to do with attitude? Is there something else?

PWLD answer 2: I think it is attitude and people not being told what it is about (having a LD). **They think because you have LD you can't learn nothing. But we learn things differently. People think we are different people but we are not, we are just like them- we just learn in a different way.** And I think they think they have to respect us more because we also contribute to the community by making it better.

Denford: Anything you would like to say about the research before we finish the interview?

PWLD answer 2: I think we need to see PWLD in power, in government. That will be a good role model for PWLD. This can help to change attitude towards PWLD by the general public. I think the media can play an important role in helping to change people's attitude. I think the media, they pity us- we don't need pity- we need to be respected. We need more people on TV and radio to have a say and be seen in a better light. I think that way (if PWLD are seen on TV) people without LD will respect us more and that is what I think. I am doing training with professionals to make them aware that PWLD can be good parents and can be part of the community.

Denford: Ok. Unless you have anything else to say, we can now terminate/stop the interview.

PWLD answer 2: Thank you very much for the interview.

APPENDIX 09: INTERVIEW TRANSCRIPT ANALYSIS (PWLD 03)

Male, very Mild LD, 46years, Attended special school, Parent, employed – intensively involved in campaigning against social services taking children from PWLD

*wants interview done in one goal

Background:

Denford: Can you tell me a bit about yourself?

PWLD answer 9: My name is x. I was born in 1965. I had good parents really, a nice family. I went to a special needs school. I found out that one of the teachers at the infant school kind of did not like me very much. She kind of wanted me out of that school because I did not learn as quickly as other children in the class. I was slightly behind and she moved me to a special school against my parents' permission. Because in the early 70s the parents did not have a say to the school that child go to. They could not say they did not want me to go a special school. They did not have that choice. I was automatically sent there because I could not read or write at that time (7years) which I

think was unfair. What happened is that I went to school x and from seven years old they put me into a special school where I stayed till I was 16 years old .

Denford: Did you have any problems at all at school?

PWLD answer 9: I was bullied all the time but I had friends, good friends. On the other hand I was bullied constantly by other people with LD on the same school. I had to buy my friendship by giving sweets so that they could not hit me or bully me. That kept the bullies away by buying them sweets. I was bullied everyday throughout my school life until one day I told my teacher about it. In the 1970s school discipline was taken seriously. The teacher had to tell the parents and tell the child off. I reported this bully to the school which reported him to his parent. Parent slapped him and that stopped him from bullying me. It affected by schooling, I did not want to go. When I was 15 year, I missed sessions – not turning up for school. I was off six months in one goal .

Denford: What had actually happened for you to be away from school for six months?

PWLD answer 9: Well I was tired of bullying, so I just wanted to be away from school. I also felt that the school was not teaching me the right things. It never prepared me for the world of work. So when I left school I found the world very scary (does not feel the school prepared him for life – to get a job and live an independent life).

2.Negative treatment/Victimisation Experiences (adulthood)

Denford: You have told me what happened to you as a child, would you like to tell me your experiences of bullying as an adult?

PWLD answer 9: I got my first job when I left school. I got finished after 3 days. I could not keep up with other workers (is it because of lack of training or being slow? It was factory work and you had to be fast to keep up the production. It was a shoe factory and had keep working fast to keep the track going- you had to put things on a track and could keep up. I got finished after two days with that one (no preparation in terms training-skills).

Denford: So it was not just the actual bullying which made you to stop working?

PWLD answer 9: Ya but a couple of bosses were bullying constantly- just commenting about my work, just stressing me out most of the time.

Denford: Any other experiences after this one?

PWLD answer 9: Some of my experiences were good. Eg the community work for the council was good. I was cleaning. I thought that was perfect and I was there for about two years. It was scheduled for that time i.e to end after two years (2 year contract).

Denford: Any problems with members of the public?

PWLD answer 9: Members of the public? Not particularly members of the public, no. It is because we were a very close family and we kept ourselves private (strategy to avoid victimisation). Other people did not know about my LD- People did not know and people cannot tell with me whether I have an LD or not. You cannot see my LD by just by looking at me. So I have not had comments by

the members of the public (not showing any physical features associated with LD helped to prevent victimisation)

Denford: You said you wanted to say something about not being treated well as a parent with LD?

PWLD Answer 9: I have never been treated fairly as a parent. Generally I got married and we had 4 years of making sure we are right for each other before having a baby. So when the baby came along, we found out that he had problems- he was not walking, talking, go to the toilet at the right time as other children would do at the same age. And the social services thought we were not good enough parents. So they wanted to take him away from us. They used our LD as an excuse to take him away from us suggesting that we were not good enough to look after him.

Denford: How did this happen?

PWLD Answer 9: It all depends on where you live-When we used to live in x, we used a different social worker. She used to come to see us play with our baby, change him, feed him. She said I am leaving, you are ok to look after your child on your own. I will leave you alone. She took us off from her list. But then we moved to place x and joined a group for children so that we were able to take him out for the summer holidays, to take him to the sea-side. So me and my wife joined this group so that we get free of charge days out with our child. After a few sessions with this group, we had a knock on the door by the social worker saying they wanted to take our child away because he needs better than average parents and you are not better than average parents. We started legal proceedings- I wanted to try to keep him and they wanted to take him away from us. I was doing a computer course at that time and I had to give that up so that I become a full time carer- the main carer. My son had a LD but I had more confidence in looking after my son- he is the first child of my own. I was married before and my ex-partner had children of her own and this is where I got experience to look after children. It was easier for me to look after children. Even my first wife had a child with LD. I found looking after my son easier (after experience of looking after my ex's children).

Denford: So they eventually took him away?

PWLD Answer 9: They took him away. We tried everything we could possible do- we also involved advocacy group to try to keep him. They put him into foster care. He has been in foster care since he was five and half years old. The only question I have to ask is this: Why did the authorities allowed me to live with my son when till he was five and half years? And take him when he was five and half years. If I was not that good they could have taken him when he was younger at two years or less when children are more vulnerable. I know that at two years children can be quite a challenge and quite demanding. That's question I am asking – why taking the child at 5 and half years. Everybody I have spoken to – not one person has ever said we are bad parents. Obviously there is nothing wrong with our parenting- it was only the social services, because of our LD and my son's LD. For me it is a miscarriage of justice – we should have kept our son.

Denford: So the court went with what the social service said?

PWLD Answer 9: This is it, and this is unfair. They are the family court. My wife had a solicitor and I had a solicitor. Because my wife is confident speaking for herself like I am, it meant that my wife solicitor had to be an unofficial solicitor to give advice to my wife solicitor of what to say in court. But the on the final hearing wife solicitor was advised not to speak in her defence. He was not allowed to say nothing in court and that left me and my own solicitor. It left me without any chance at all. So we ended up losing him.

Denford: How did you feel about this experience?

PWLD Answer 9: I was devastated. I tried to be strong for my wife's sake and for the child. The first thing after they had taken him away, that we could have contact with him. But there is a rule of contact- if the child cries on contact, and if either my wife or myself cry contact will be stopped. Neither the child nor us as parents are allowed to show emotions. They have told us this morning and before then, we are not allowed to show any emotion what- so- ever. So I said to the social worker alright then what you are saying is: I am I supposed to act out like what you see on the TV- doing an acting job. She said if you want to put it that way then you have to act it out. Try to create a positive environment for him. This is what it is like now (our situation now). This happens in this country and I am ashamed to be British to honesty with you. I am ashamed of being a British citizen. To allow children to be taken away from their parents who want to look after their children, parents who have done nothing wrong.

Denford: Do you think there are parents with LD experiencing the same?

PWLD Answer 9: Oh yes and worse. I know some parents who lost their child the day or the moment it was born- taken from their mum from birth straight away. No bond, never got the chance to bond with baby or have a relationship with it. So I fight for the right of PWLD to keep their kids now.

Denford: Do you have other experiences of bullying/ unfair treatment affecting other PWLD you know?

PWLD Answer 9: There was a neighbour (with LD)

I can remember. He used to be called names a lot. He used to walk around the street kids used to hit him and make funny of him- he had LD and down syndrome as well. That's the only incident I can relate to.

Denford: Did that PWLD live on their own or it was a residential home- where did he live?

PWLD Answer 9: I think he lived with his family and their neighbours who lived on the same street as me.

Denford: Are you able to tell me whether PWLD are being victimised more or less? Is it getting better or getting worse?

PWLD Answer 9: I think it is more in the area of parenting. The thing I think though, this only my opinion, I think the biggest mistake a person with LD does is telling other people that they have a LD. That opens up to victimisation. Whereas me I just keep it to myself- nobody knows outside this

building except for my wife. For me as I am growing older, you can't see it the same. You can see it when I do writing I can't spell but when I speak and doing other things- a bit slow. I work(speak) with many people – I have spoken to judges, solicitors, social workers and I have been on the news and I have spoken at conferences. And people comment afterwards and say you haven't got a LD. And that's come from social workers- because they can't see it in me by just talking to me or looking at me.

Denford: So you think the situation is not getting any better?

PWLD Answer 9: Certainly not. At the moment I don't feel I am not listened to. My son is 12 now and will be 13years next and is starting to have more of an opinion for himself. He is asking to come home but the social service they say I have got to live in a house rather than in a flat for that to happen. He wants to come home but I have to move house. Because I am living in a flat and that's not suitable- I have to get a house.

Denford: Are there no children in those flats you live?

PWLD Answer 9: In those flats NO.

Denford: Anything else you would like to say with regards to the bullying or unfair treatment of PWLD?

PWLD answer 9: I am happy to move to the next question please.

3. Quality of life:

Denford: Are satisfied with the quality of life you live?

PWLD Answer 9: We are able to do what we want to do- we do not have people telling us what to do and what not to do. That's a good thing. But it is just that I don't feel I am taken seriously. I don't feel I am listened to- **the issues with my child has taken over everything. It is the number one thing at the moment.** I have to find somewhere to live so that my son can come home. I want him to come back and has been crying to come home. If I was to go to court now, the council will say the flat is not suitable. NO.

Denford: So this time it will not be about having LD but about not having appropriate accommodation?

PWLD Answer 9: Oh yes. **I have had an apology. I have had one apology that I should not have been treated that way by the social workers. I have been told that things are no longer done the same way but I do not know the truth about that. But I have had an apology for taking him away just like that.** When we were going through the court process, we had a social worker working with us. And she at that time did not want the child to go into care. But she had a meeting with someone higher in authority. After that meeting things changed –they now said we want to go to court to put that child into care. The result of that meeting ended up that social worker got physical ill and ended finishing the job. But not feeling ill but because she was disgusted by the way professions treated parents with LD- it is like that she quit the job. She is not doing that job anymore and now works in a local supermarket. – She told I should have kept that child. Then a younger woman took over as my son's

social social worker. She got to get the career ladder and all she wanted was that he be taken away. The other lady was older and more experienced- she had more knowledge/understanding of parents with LD. This younger one who did not have a long time in the job, either to please the superior bosses just wanted him to be taken into care. And that's what happened.

Denford: So you are saying this issue has taken over everything and has caused you a lot of anger, devastation.

PWLD Answer 9: Definitely. I got depression and became suicidal, it nearly drove my wife to commit suicide. She ran away along the dual carriageway, a busy road and she walked across that road not bothering to look around. She nearly got run over. Luckily it did not happen.

Denford: What impact did or does it have to the child?

LD Answer 9: With our son- what happens to him, whether in care or with us- we always tell him we love him. I don't think it has affected him actually, we told him we loved him each time we visited him. He is happy and smiling all the time. He is doing well at school. Today I have been to his school and has an excellent report. I don't think this has affected him. All I can do is protect him and fight for his future. That's my intention why I come here to help other parents and campaign to change the law so that parents keep their children. But also because my son will soon become an adult and want him to keep his children. I do not want him to go through what I am going through. That's why I campaign to put a stop to it. I was nearly put in prison for it- for campaigning. I did a conference 4 years ago when I worked for an advocacy group. I was asked to go on interview on TV by my manager. I was not supposed to talk about my court case on TV but luckily enough I did not use names- thank goodness. I got advice not to use names including mine). It worked and that stopped me from sent to prison.

Denford: This was going to cost more than just your child it could have cost you your freedom.

PWLD Answer 9: I could have cost me my freedom as well but I will continue to campaign. On a positive note though, at the time of the news report, the social worker wanted my contact with my son to two times a year, because they wanted him to get adopted you see, I would not sign the papers for him to get adopted. They took me to court because I did not want to sign the papers and when I appeared on TV and talked about them wanting to reduce my contact times, it ended up the social workers losing the right to adopt my son and losing the power to cut my contact to twice a year. So I get six times a year now. He visits my home at Christmas and birthdays.

Denford: How did you deal with all this?

PWLD Answer 9: Well, how I deal with it emotionally?- it is probably my faith, my Christian faith in Jesus and God that gives me the strength to carry on.

Denford: Do you think you get support from others to deal with such issues?

PWLD Answer 9: I do, I do- I have my wife's parents and I have got some friends as well. When I worked for organisation X for PWLD, when I lost my child the first thing into my mind was I must

be the only parent who has experienced such a thing- that's what I thought. When I met other parents who have also lost their children, we were able to share with each other and cry with each other. I had depression then- it made me get depressed and took tablets for it. So did my wife. Talking to other parents who had also experienced the same as us, it resulted in improving the depression and in making great friendships and I am still friends with those friends even today. We get in touch with each other.

Denford: What about the this advocacy here, which you attend?

PWLD Answer 9: The parent group? This consists of these friends from CHANGE- we just wanted to carry it on for the parents to keep their children. The funding is running out now. I am no longer employed by organisation x for PWLD and have joined hands with ADVOCACY staff here to form this parent group. We now want to form a rights group for parents- that's what we are doing at the moment. I won't stop until justice has been done – till I see change for parents and children for with LD. Just like William Wilberforce campaigned to get rid of slave trade, I want to do the same with the issue of parent with LD losing their children. **It is not a crime to have an LD, if it is abuse, sexual abuse, physical abuse- that's a different matter. PWLD who love and want their children that is not a crime. So why do you lose your children because of that. We did not have a choice to enter this world. So I won't stop until something changes.**

Denford: so here the police did not help?

PWLD Answer 9: Oh no, because the police is not involved in the family case/court. In a family court it is an open and short case. You have a LD and we are going to take your child, it is all secret and no one is allowed to talk about the case besides the court.

Denford: What changes do you want and .. ?

PWLD Answer 9: My ambition is doing this parents group- I want to see the government face-to-face, David Cameron and talk to him face-to-face. Try to bring about change to government practice and change the way judges treat PWLD. Also want to do a protest march against the injustice.

Denford: Do you have anything else to say with regards to ways PWLD try to prevent further victimisation?

PWLD answer 9: I have said a lot and happy to move to the next question

4. Causes of victimisation

Denford: Why do you think PWLD are targets of victimisation/negative treatment (bullying, unfairly treated)?

Answer 9: I don't really know. **I think it has got to do with society's negative attitudes. If you are deemed as having a LD, people change their opinion of you.** Even their voices change- I remember an incident of someone talking to a person with LD, they were just talking just general talk and then the person told them they had a LD and if they could explain things a bit more. They changed the way they talked to the PWLD and started talking to them in a patronising manner as if you are

thick. So its just attitude- the number one thing is to change attitude. But this can happen through doing some campaigning – things like looked after children conferences, talk about parents with LD in conferences. Something good happened this year as a result of these campaigns. It has resulted in two sets of parents in keeping their children. It is because it changed the perception of the social worker who attended the meeting through what we said and made him think. A friend of mine – 3 of her kids were taken away and she got pregnant again and has managed to keep the child this time. Me and my wife we have not had another child because we are frightened that if we do, it will be taken away and I can't do to lose another child.

Denford: What will be your conclusion to whole issue of how PWLD are treated?

PWLD Answer 9: My conclusion is that people's attitude is not good and they have to stop this bad attitude and start treating PWLD like human beings. In the past whites and blacks did not sit next to each other on the bus, but now they do. Today what proves difficult is accepting PWLD. It the same case with gay and lesbians, that was victimised many years ago but now everybody accepts that. It should be the same now with PWLD, they should be accepted just like any other person in the community. That's what I want to see change. We are at the bottom of the pile, where gay people where many years ago. The only thing that has changed is the institutions, go back 50 years PWLD would have been institutionalised. But this does not happen anymore as far as I am aware. This is what I want to change- I want PWLD to have children and keep them. And that PWLD be treated the same as everybody else. These are my views because I don't want my child to suffer the same as I did when he is older.

Denford: Unless you anything else to say. We can terminate the interview now.

PWLD answer: Nothing else to say. Thank you very much.

APPENDIX 09 CONTIUED: EXAMPLES OF EMERGING THEMES

<p>Bullied throughout school life Buying friendships with sweets to reduce/avoid being bullied Reporting bullying to Teachers who reported to parents Poor quality of education/ education not of any value to his life in adulthood Left school because of both the bullying and poor quality of education Not able to keep job: lack of work related skills distressing negative comments from others about his work performance Low paid and manual job Hiding LD: do not tell anyone, mask signs and symptoms of LD Hiding LD reduces negative treatment Denied opportunity to parent their own child- child taken ware by social services and put into care</p> <ul style="list-style-type: none"> • Never explained what was wrong with their parenting skills/abilities • Efforts to fight to keep child did not work as professionals support each other • Having an LD seen as main reason why child is taken away from them • Professionals taking control of both the child's and parents lives: decides where the child lives, forces adoptions against parents' wishes, 	<p>Ashamed of being a British citizen because of the way he has been denied rights to parent own child and child denied family life Aware of other parents who have had their children taken away Aware of other PWLD who have unfairly treated in public places: hit, called names, Their quality of is better mainly because they are able to live independently (no one telling them what to do)- it is not about material things Losing child has caused far reaching consequences: mental health problems- depression, suicidal ideations, becomes the only thing they think about and nothing else Professional concerns not the parent or the child but personal gains (professional ambitions) got the strength to cope and come into terms with their loss from their Christian faith, support group of parents with LD, advocate group, and the fact that he needed to be strong for his wife and child Negative societal attitudes towards PWLD is at the heart of their unfair treatment PWLD with LD's treatment worse than that of any group = society is finding it harder to accept PWLD compared to what they with homosexuals and black people</p>
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<p>controls number of visits and how the visits should be done</p> <ul style="list-style-type: none"> • Both parent and child not listened to: Parents want to keep their child and child wants to come home 	<p>Changing attitudes must be given priority Campaigns to change attitudes is the way forward PWLD, Government, TV /media and advocate groups should all have a big role in changing attitudes</p>
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APPENDIX 09 CONTINUED: ANALYSIS OF TRANSCRIPT 01

Examples of Emerging Themes Clustered into four areas of the Research question

<p>Nature: Education: Bullying Poor quality of education</p> <p>Employment: Lack of work related skills Bullying Low paid job (cleaning)</p> <p>Family: Denied the opportunity to parent own child (child taken into care)</p> <ul style="list-style-type: none"> • Professionals in control of their parental lives: decides where the child lives, forces adoptions against parents' wishes, controls number of visits and how the visits should be done • Both parent and child not listened to: Parents want to keep their child and child wants to come home 	<p>Impact: -Mental Health Problems: depression, suicidal ideations -Psychological problems:</p> <ul style="list-style-type: none"> • Becomes the only thing which overwhelms the mind; • Ashamed of being a British citizen because of the way he has been denied rights to parent own child and child denied family life • Deep feelings of none acceptance by society and believing that PWLD are the least wanted people in society (at the bottom of the list and treated less than homosexuals and Black people) • Afraid of having another child – may be taken away again • Scared of getting a job: lack of work skills <p>-Not completing secondary education – poor quality of education and bullying -Poor quality of life: low paid job, overwhelmed by issue with child taken away -Powerlessness: Life controlled by professionals</p>
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<p>Causes: Society's negative: the major cause Having a LD: When people do not know you have LD , they treat you better Professional ambitions given priority at the expense of PWLD's rights to live ordinary lives Different professionals supporting each other</p>	<p>Strategies to cope with, come into terms with and prevent further negative treatment:</p> <ul style="list-style-type: none"> -buy friendship to prevent further negative treatment -avoidance: leaving school, leaving the job -Confronting the problem: Involvement in campaigns , conferences with professionals in trying to improve the situation -Strengthening faith in Christian beliefs
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APPENDIX 10: IDENTIFYING MARGINALISATION

<u>Experience of Oppression:</u>	<u>Causes/Experience of Oppression:</u>
<p>Public Places/spaces:(members of the public) -name calling, physical aggression, intimidation, damage to property (eg homes, bus stops PWLD use), -discrimination: unwelcome in cafés/restaurants/pubs, no disabled access to pavements & buildings -Bullying and harassment -hate crime -mate crime -financial abuse</p> <p>Education: -segregated SEN schools, -Lack of credible education: poor quality skills & knowledge, not able to complete secondary education, lack of basic qualifications to access higher education and job training courses, bullying, harassment, sexual abuse</p> <p>Employment: Unemployed, lack of opportunities for credible employment, menial jobs, low paid jobs, lack of relevant work skills and knowledge, employers not will to invest in</p>	<p>Society/Public -Society's negative attitudes: seen as useless, unable, incapable, people who require pity/sympathy and need to be looked after -Misunderstanding -Ignorance -hatred -Lack of acceptance of PWLD</p> <p>PWLD -Weaknesses related to having LD impairments (cognitive, physical and functional) -Socially unacceptable behaviours -Stigma associated with LD label -weak identify -Dependence on others and services</p> <p>Family - Not able to cope with LD behaviours -Difficulties coming into terms with disabilities of family member/child -Protection of PWLD -Lack of skills in caring for PWLD</p> <p>Professionals</p>

<p>professional development, bullying, harassment,</p> <p>Family:</p> <ul style="list-style-type: none"> -being placed into care/institutions, -abandoned at very young age: left in care as babies, rarely visited, not visited at all & left at the mercy of services -Over protection which impacts on independent living skill & creates dependence -feeling unwanted/disliked because of having LD (not the perfect child) -taken for granted that they do not have good parenting skills because of their LD -sexual abuse, financial abuse <p>Professionals and Institutions:</p> <ul style="list-style-type: none"> -having their taken away from their care (midwives, social workers, courts) -lives controlled by professionals and services -neglect -financial abuse -sexual abuse 	<ul style="list-style-type: none"> -Labelling PWLD -Controlling learning disabilities services/industry -Lack training, skills, -Heavy work load -Easy access to the vulnerable
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Key:

All highlighted in yellow were identified as forms of marginalisation.

APPENDIX 10B: SUB-THEMES OF MARGINALISATION EXPERIENCES

Nature & Causes	Impact & Reaction
<p>Experiences of Socio-economic Environments</p> <p>Weak socio-economic status: Lack of social or political empowerment</p> <p>-Weak social identity: Stigmatised</p> <p>Experiences of Education:</p> <p>-Special Educational Needs: Institutional aspect of it-Special Educational Needs: Quality of education</p> <p>Experiences of Employment</p> <p>- Poor literacy and lack of work-related skills</p> <p>-Unemployment or menial jobs</p> <p>Experiences of Family Life</p> <p>-Abandoned/ disowned by parents or family</p> <p>-Childhood defined by institutional life</p> <p>Experiences of working with Professionals</p>	<p>Impact of Marginalisation</p> <p>Material Deprivation & Limited social mobility Poor education, lack of skills, no work/income, -Denied opportunity to create own family life</p> <p>Few Opportunities for Leisure or Establishing Social Relationships</p> <p>Weak Social Status</p> <p>-Weak identity</p> <p>Individual Powerlessness (lack of self – autonomy)</p> <p>Professionals in control and protective parents leading to dependency</p> <p>Social/Political Powerlessness (No one is listening)</p> <p>No family support, poor education, no economic power and low social status</p>

<p>-Professionals in control of LD Children -Professionals in control of LD Adults</p> <p>Causes:</p>	<p>Loss of sense of identity and self –respect Stigma Poor social status and unable to contribute</p> <p>Poor Mental Health & Self – isolation Depression, anxiety, loneliness</p> <p>Reacting and Coping with Marginalisation</p> <p>Accepting or Lacking of awareness of their marginalisation -Put up with it -Internalise their pain</p> <p>Seeking Official Interventions - Financial benefits -Better housing -Training</p> <p>Purposive Resistance - Take voluntary work, - Keep own children out of SEN</p> <p>Assertive Action - Campaigns for change</p>
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APPENDIX 11: IDENTIFYING VICTIMISATION EXPERIENCES

<u>Nature of Oppression:</u>	<u>Causes of Oppression:</u>
<p>Public Places/spaces:(members of the public)</p> <ul style="list-style-type: none"> -name calling, physical aggression, intimidation, damage to property (eg homes, bus stops PWLD use), -discrimination: unwelcome in cafés/restaurants/pubs, no disabled access to pavements & buildings -Bullying and harassment -hate crime -mate crime -financial abuse <p>Education:</p> <ul style="list-style-type: none"> -segregated SEN schools, -Lack of credible education: poor quality skills & knowledge, not able to complete secondary education, lack of basic qualifications to access higher education and job training courses, bullying, harassment, sexual abuse <p>Employment:</p> <p>Unemployed, lack of opportunities for credible employment, menial jobs, low paid jobs, lack of relevant work skills and knowledge, employers not will to invest in</p>	<p>Society/Public</p> <ul style="list-style-type: none"> -Society's negative attitudes: seen as useless, unable, incapable, people who require pity/sympathy and need to be looked after -Misunderstanding -Ignorance -hatred -Lack of acceptance of PWLD <p>PWLD</p> <ul style="list-style-type: none"> -Weaknesses related to having LD impairments (cognitive, physical and functional) -Socially unacceptable behaviours -Stigma associated with LD label -weak identify -Dependence on others and services <p>Family</p> <ul style="list-style-type: none"> - Not able to cope with LD behaviours -Difficulties coming into terms with disabilities of family member/child -Protection of PWLD -Lack of skills in caring for PWLD <p>Professionals</p>

<p>professional development, bullying, harassment,</p> <p>Family:</p> <ul style="list-style-type: none"> -being placed into care/institutions, -abandoned at very young age: left in care as babies, rarely visited, not visited at all & left at the mercy of services -Over protection which impacts on independent living skill & creates dependence -feeling unwanted/disliked because of having LD (not the perfect child) -taken for granted that they do not have good parenting skills because of their LD -sexual abuse, financial abuse <p>Professionals and Institutions:</p> <ul style="list-style-type: none"> -having their taken away from their care (midwives, social workers, courts) -lives controlled by professionals and services -neglect -financial abuse -sexual abuse 	<ul style="list-style-type: none"> -Labelling PWLD -Controlling learning disabilities services/industry -Lack training, skills, -Heavy work load -Easy access to the vulnerable
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APPENDIX 11B: SUB-THEMES OF VICTIMISATION EXPERIENCES

Nature & Causes	Impact & Reaction)
<p>Victimisation by the Public</p> <p>Harassment</p> <ul style="list-style-type: none"> -Bullying -Verbal abuse -Physical abuse -Financial abuse -exploitation -Discrimination in public places -Damage to property -Psychological abuse <p>victimisation at workplace</p> <p>Bullying</p> <ul style="list-style-type: none"> -Harassment -Physical abuse -Sexual abuse -Discrimination -Financial abuse <p>victimisation by family</p> <p>Financial abuse</p> <ul style="list-style-type: none"> -Sexual abuse -Neglect 	<p>IMPACT OF VICTIMISATION</p> <p>Changes in Lifestyle & Routine Changing : travel routes, venues and mode of transport</p> <p>Dependence on others Fear and sense of insecurity</p> <p>Secondary Victimization -Further victimisation by police -Also affecting others: close family and carers</p> <p>Psychological, Mental Health & Behavioural Problems Depression, anxiety, suicide, self-harming, isolation and loneliness</p> <p>Criminal Offending & Detention in secure institutions</p> <p>Mental health problems, influence of alcohol and drugs, anger</p>
<p>Victimisation by Professionals & Private institutions</p> <ul style="list-style-type: none"> -Sexual abuse 	<p>REACTING TO VICTIMISATION</p> <p>Accepting</p>

<ul style="list-style-type: none">- Financial abuse- Verbal abuse- Neglect- Discrimination- Negative publicity by the media	<ul style="list-style-type: none">- 'Putting up with it' victimisation- Lack of awareness of their victimisation <p>Avoidance Taking precautionary measures</p> <ul style="list-style-type: none">- avoid certain routes, times of travel, mode of transport- Stopping going outNot to carry cash- Carry mobile phone- walk in groups <p>Defensive</p> <ul style="list-style-type: none">- Training in self defence- Carrying weapon <p>Seeking formal and informal help</p> <ul style="list-style-type: none">- Reporting to family, Police, Staff and other PWLD- Counselling <p>Assertive Action</p> <p>Campaigns in schools, with the police and other professionals</p>
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