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Disability, relative poverty and gender: How men with learning disabilities perceive and experience the impact of social divisions on their health

By

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Declaration

The thesis and the work on which it is based are the sole work of the author.

The degree has not been submitted for a degree at another university

The research has been undertaken in accordance with the University safety

policy and Guidelines on Ethical Practice

Abstract

This thesis explores how men with mild to moderate learning disabilities perceive and experience how disability, relative poverty and gender impact on their health. Its theoretical framework grounded in analysis of these social divisions, and informed by the men's own accounts - previously neglected in research, reveals complex challenges affecting their health on a daily basis.

Consistent with the thesis' overarching perspective, key elements of a participatory approach were adopted in the fieldwork to ensure men with learning disabilities' active research involvement. They comprised the steering group, and twenty men participated in qualitative interviews facilitated by accessible materials and detailed preliminary preparations.

The findings showed the men were aware of health issues, but were grappling with the adverse health effects of impairment, including disabilist health care and victimisation. Low income associated with limited employment confined most men to relative poverty with negative effects on health. The findings demonstrated a sharp appreciation of masculinity. Marginalised by other men, they experienced health threatening abuse, but their resistance to conventional male disregard for health care, had positive implications for their health.

The thesis provides a more informed, nuanced understanding of the adverse impact of different dimensions of social disadvantage on the health of men with mild to moderate learning disabilities. In doing so, it demonstrates the value of developing knowledge grounded in their perspectives and experience.

Chapter One

Introduction

Rationale

This thesis explores how men with learning disabilities, from their own perspective, experience and understand the effects of key social divisions on their health. Whilst a growing body of research exists that seeks to involve people with learning disabilities in research on a number of topics (Zarb, 1992; Walmsley and Johnson, 2003; McClimens, 2010), little is known from men with learning disabilities themselves about the impact of social divisions on their health, and their views on this. This thesis aims to address this issue by exploring how men with mild to moderate learning disabilities experience and perceive respectively, the impact of disability, relative poverty and gender on their health.

In undertaking this research, the thesis does not simply focus on ill health, but adopts a more comprehensive view of health in day to day life, as described and experienced by the participants. While primarily focusing on participants' experience of physical health, the thesis also takes account of the way in which physical and mental ill-health are intertwined.

In adopting a social divisions approach as a conceptual framework, the thesis is focusing on the ways in which men with learning disabilities are positioned socially, or their social position is stratified, according to

differences associated with social inequality (Graham, 2009). The analysis of social divisions has evolved to encompass a range of dimensions in addition to disability, relative poverty and gender, also including ethnicity, sexuality and age (Payne, 2006). While acknowledging the importance of the range of social divisions, the rationale for the thesis focusing on the categories of disability, relative poverty and gender as tools of analysis that enable the researcher to explore the health of men with learning disabilities, is discussed in detail next. In doing so, it is not suggested that the lives of men with learning disabilities can simply be viewed in terms of each category on its own. Clearly, each category overlaps with each other, with the potential to impact on the health of these men.

There has been a growing concern that people with learning disabilities are subject to disabilist attitudes and approaches, resulting in their health needs being consistently undetected and unmet. Following a number of tragic deaths, the independent report *Healthcare for All (*Michael, 2008*)* set out serious concerns about inequalities in healthcare for this group of people. The Joint Committee on Human Rights report (2008), *A Life Like Any Other,* found that a wide range of health care services were depriving people with learning disabilities of their basic rights. Abraham and White (2009) noted in their report, *Six Lives: The provision of public services to people with learning disabilities*, the need for an urgent review of the systems used within the National Health Service, to meet the additional and complex needs of this group of people. Further evidence highlights how people with learning disabilities receive fewer screening tests and fewer health

investigations in primary health care, when compared with the non-disabled population (Disability Rights Commission, (DRC) 2006). This situation is compounded by the existence of a range of serious health conditions, which occur more frequently within the learning disabled population when compared with the non-disabled population (Howells, 1986; Beange et al, 1995; Cooper, 2004; Lantman-de Valk and Walsh, 2008). These include epilepsy, coronary heart disease, respiratory disorders, mental ill-health and hearing and sight difficulties (Department of Health, (DH) 2001; Lantman-de Valk, 2009). However, little is known from the perspective of men with learning disabilities about the impact of disabilist attitudes and interventions on their health, and therefore this forms one major focus of this thesis.

The thesis also focuses on a further neglected dimension to men with learning disabilities' experience of and perspectives on the impact of social divisions on their health. This is the known association between relative poverty and unequal chances of health and life expectancy in the general population (Townsend and Davidson, 1982; Wilkinson, 1996; Lynch et al, 2000; DH, 2010). Relative poverty has been found to characterise the existence of people with mild (see below page 5) learning disabilities (Emerson et al, 2009). Disabled adults, including people with learning disabilities are twice as likely to live in low income families as the non-disabled population and out of the 8.5 million disabled people of working age in the United Kingdom (UK), less than half are in paid employment (www.poverty.co.uk, 2008). Most people with a mild learning disability also live in disadvantaged social areas (DH, 2001; Chapman et al, 2008;

Emerson, 2010). However, very little is known about the impact of relative poverty on the health of people with learning disabilities. Furthermore, the experience and views of men with learning disabilities themselves, on the significance of living in relative poverty for their health remains unexplored.

The remaining social division this thesis explores is that of the impact of gender on the health of men with learning disabilities. There has been extensive research on the negative effects of gendered attitudes and behaviour on women's health, as in domestic violence perpetrated by men, constituting a serious health risk for women (Hague and Mullender, 2006; Humphreys, 2007). Work has also been undertaken on gender and the health of women with learning disabilities (McCarthy and McMahon 2008; McCarthy, 2009). However, whilst there has been developing interest in gender as it affects men's health generally, including its negative effects (Connell, 1995; Courtenay, 2000; O'Brien et al, 2005), the gendered nature of the health of men with learning disabilities remains marginalised in research. Much of the research on men's health still tends to view men as a homogeneous group and the debate is only gradually being extended, for example, to men from different ethnic, and socio-economic backgrounds or disabled men (White, 2006). This thesis therefore aims to explore the gendered ways in which social disadvantage may impact on the health of men with learning disabilities, and their perceptions of this.

People with learning disabilities therefore emerge as a marginalised social

group who experience a range of physical and mental health conditions associated with cognitive impairment (DH, 2007) and various forms of social disadvantage (DRC, 2006). Learning disability has been classified into four categories, mild, moderate, severe and profound (Diagnostic Statistical Manuel IV, (DSM) 2004). Assessments attempting to characterise the differences between these classifications are based on two main areas, namely the individual's intellectual/cognitive ability and the way in which they adapt in social situations (DSM IV, 2004). People with severe and profound learning disabilities' impaired cognition means they are more likely to have serious speech/communication difficulties and be less aware of their surroundings. They frequently require assistance from others for most of their daily needs. In comparison, people with mild to moderate learning disabilities, may have developed literacy skills and are able to live independently with minimal support from others (Foundation of Learning Disability, 2006).

Whilst this study does not preclude the importance of its focus to men with more severe learning disabilities, it initially seeks to test out its subject area in an introductory and indicative way, with men with mild to moderate learning disabilities. There is limited research that has explored the impact of the key social divisions on the health of people with learning disabilities. Given the complex nature of these social divisions, it is acknowledged that it would be challenging to gain perceptions and experiences on them from people with more severe learning disabilities. However, by foregrounding understandings of this topic initially with men with mild to moderate learning

disabilities, it is hoped the new knowledge gained will provide a starting point, which will enable the topic to be accessible to men with more severe learning disabilities in the future.

My interest in the subject of this thesis stems from my knowledge as a learning disability nurse and from research I carried out earlier. My research with people with learning disabilities, carers and their General Practitioners (GPs) on attending appointments at their local practice, highlighted varying roles the carer and GPs undertake, which can negatively influence the outcome of the consultation process (Bollard, 2003). This enabled me to become increasingly aware of factors that can impinge negatively on the health of this particular group of men. Working with this group of men also gave me an insight into how their living circumstances, a lack of money and the set of specific health conditions accompanying learning disability, meant they were living with various forms of disadvantage. All of these carry a potential risk for eroding their health. More men than women are also affected by learning disability and its associated disorders, such as autism (Emerson et al, 2010). These factors, together with my awareness of a tendency towards health damaging behaviours among men, such as a reluctance to seek medical help (Payne, 2006) encouraged me to gain a deeper understanding of men with learning disabilities' perspective on their health.

Theoretical context

Disability: a contested perspective

Until the 1970s, bio-medical understandings of disability were dominant and little attention had been paid to how social conditions could affect the everyday lives of disabled people and lead to their exclusion within society (Thomas, 2007). With the development of the Disability Movement over the last four decades, disabled people have sought to promote their own civil, social and political rights, to remove the social conditions and barriers that they experience as oppressive and the main cause of their social exclusion (Oliver, 1996; Oliver, 2009). Subsequently, other scholars have made attempts to offer an even fuller explanation for the predicament disabled people face. They have argued that both the effects of different forms of impairment, as well as social discrimination, in the form of disability affecting disabled people's existence, need to be accounted for (Crow, 1996; Shakespeare, 2006). However, this debate has largely been aimed at disabled people in general and rarely been applied to people with learning disabilities (Goodley, 2001; Goodley and Hove, 2005).

There has been some specific evidence on social factors with the potential to impinge negatively on the health of men with learning disabilities. This relates to the increasing evidence of victimisation and disability hate crime targeted at this group of people (Thomas, 2010). Other disabling social factors identified as affecting the health of men with learning disabilities, relate to their reduced social networks and friendships and the potentially

negative impact this has for psychological health (Wilkinson, 1997; Hardy et al, 2002). This thesis explores how men with learning disabilities themselves, understand how both cognitive and physical conditions associated with learning disability, the 'impairment effects', combined with disabling circumstances can impact on their health.

A socio-economic perspective

People with learning disabilities are amongst one of the most economically disadvantaged groups in society: they are exposed to adverse material factors, such as reduced income and employment chances (DRC, 2006). A disabled adult's risk of having a lower income is much greater than that of non-disabled people, across all family types, such as lone parents, nuclear and extended families (Birchenbach, 2011). Most disabled people are reliant on some form of income support (www.poverty.org.uk, 2008) and compared to national average income, people with learning disabilities fall into the lowest quintile (Marmot, 2010). In terms of employment, estimates indicate that less than 10% of people with learning disabilities are in paid employment (DH, 2009) and gaining and holding on to employment remains a challenge for many people with learning disabilities (Broad, 2007). These reduced socio-economic factors are more likely to place the majority of people with learning disabilities in relative poverty (Emerson, 2010). Studies are attempting to explain the process whereby social inequalities impact on health (Lohan, 2007). Health has been seen as the outcome of the complex interplay of factors associated with the circumstances under which people

live their daily lives, such as quality of housing, choices over diet and their relationships within their neighbourhood (Lohan, 2007). Yet this literature has not explored what this means for men with learning disabilities, in terms of what they may have to go without and the resultant impact on their health; nor how they perceive the effects on both their physical and psychological health.

A gendered perspective

The health of men has increasingly become a public health concern (Robertson, 2007). Patterns of men's health are highlighted as containing certain negative features in comparison to women's health, with men in the UK currently having a five year reduction in life expectancy compared to women (Office of National Statistics, (ONS) 2007), and more likely to die prematurely than women, from the ten most common cancers (Payne, 2006). This is frequently explained by the way in which men behave in relation to their health, through adopting health damaging behaviours such as cigarette smoking, excess alcohol use and fast driving and being less likely to seek health advice and access health services (Royal College of General Practitioners, 2005). Whilst some work has explored men with learning disabilities' engagement with substance abuse (Taggart, 2006), no work has explored whether men with learning disabilities adopt the same health damaging behaviours as non-disabled men. The existence of specific health conditions associated with this population, highlighted earlier, and the known health damaging behaviours linked to men in general, may place

these men at a potential risk of double disadvantage in relation to their health.

Sociological studies have begun to recognise that men may 'practice' and construct masculinity in relation to their health in varied ways (Connell and Messerschmidt, 2005; Courtenay, 2011). In recognition of the structural differences between groups of men, it is now commonplace to refer to the diverse and fragmented nature of masculinity as 'masculinities' (O'Brien et al, 2005). However, apart from a few studies showing how care staff in the course of their practice, have tried to inculcate ideas of masculinity for men with more severe disabilities (Wilson, 2005; Wilson et al, 2009), this debate has not previously been extended to how men with learning disabilities themselves, understand and perceive masculinity and its impact on health.

Research objectives

Drawing on my previous professional practice and research, together with systematic analysis of existing literature, the main research objectives of the thesis are:

- To contribute to understanding the impact of social divisions on the health of men with learning disabilities.

- To do so by foregrounding the experience and perspectives of men with learning disabilities.

- To focus on exploring disability, relative poverty and gender as potentially key dimensions to the impact of social divisions on the health of men with learning disabilities, from their own standpoint.

Research questions

The following research questions inform the empirical study:

- How do men with learning disabilities experience the impact of disability on their health and what is their perspective on this?

- How do men with learning disabilities experience and understand the effects of relative poverty on their health?

- How do men with learning disabilities experience and make sense of their masculinity and the way in which it affects their health?

Fieldwork strategy

Empirical theoretical perspectives

The empirical study informing this thesis sought to support the active involvement of the men in the research and facilitate access to their views and experiences. It was therefore aligned to a participatory approach, comprising some of the key elements of this approach, as described by Northway (2010). Whilst it is acknowledged that there is no established way in which this approach can be undertaken (Condor et al, 2011), a participatory approach to research has certain common features, for

example a commitment by the researcher to tilt the balance of power in favour of the research participants (Northway, 2010). It emphasises the value of seeking out different ways to include disabled people in research (Priestley et al, 2010) and departs from previous approaches that viewed, in particular, people with learning disabilities, as subjects of research, rather than participants (Kiernan, 1999).

The empirical study also adopted a qualitative approach to interviewing. The aim of this is to provide the opportunity to elicit a deeper understanding of the way in which this particular population of men 'go about' their daily lives and the social context in which they do so (Denzin and Lincoln, 1994), from their own standpoint. The ways in which the researcher facilitates involvement and seeks to develop a relationship with the participant is also integral to qualitative research (Miller et al, 2009) and was also a key concern in the study.

Methodology

Consistent with the perspectives highlighted above, two different groups of men with mild to moderate learning disabilities were involved in the research; as steering group members, and participants through semi-structured interviews. As steering group members, the men participated in developing and reviewing key documentation. They also provided guidance and acted as a 'sounding board' in reviewing accessible pictorial

documentation and other printed interview materials, as well as providing feedback during and after field work.

Twenty men with mild to moderate learning disabilities were interviewed, using a semi-structured approach, and employing a range of initiatives and aids such as careful preparatory meetings, visual aids, and accessible language to facilitate participation. Attention was paid to ways of concretising otherwise relatively abstract concepts such as disability, poverty and masculinity, in order to ensure that the substance of the interview process was accessible for the participants. This enabled me to be responsive to the men's individual levels and forms of conceptualisation, methods of communication, and to draw out their understanding on the key topics of the research.

Limitations

Given the confines of this thesis, it does not cover the impact of further social divisions such as racism and homophobia in relation to their impact on the health of men with learning disabilities, and the men's perception and experience of this. Furthermore, this account cannot seek to represent the experience of all men with learning disabilities. For example, while the health status of people with learning disabilities in residential care is an important area for exploration in its own right, this study does not focus on residential care, as for the most part people with less severe learning disabilities do not live in residential care (Emerson and Baines, 2010). It is

also recognised that the empirical study is limited in that the accounts are from a relatively small sample of white men and represent the views of this particular group of men, but hopefully it raises a series of significant issues that can be explored in more extensive studies. Research accounts are also co-constructed between the participants and the researcher and this process influences how the accounts are interpreted and portrayed. In this case the interview is conducted between two men. As such, my masculine identity may influence what the interviewee considers they should say, as a man and my interpretation may be affected by my masculine identity (Oliffe, 2009). As an able bodied researcher conducting research with a disabled group of men, I also needed to continually reflect on the processes in which I involved the men, so as not to further marginalise them in any way.

Organisation of the thesis

Chapter 1 Introduction

This chapter provides the rationale for the research, and locates the formulation of the research objectives and questions, in their theoretical context. It then provides an analysis of the strategy informing the empirical study. In addition to introducing the theoretical perspectives shaping the fieldwork, it also introduces the features of the research process necessary to promote the engagement of men with mild to moderate learning disabilities in the research. Some of the limitations to the research are put forward to conclude the chapter.

Chapter 2 The significance of disability for the health of men with learning disabilities

This chapter is the first of three setting out the theoretical context of the thesis. It reviews the traditional medical understandings of disability. It then discusses the emergence of the disability rights perspective and charts the position of people with learning disability within this perspective in the UK. It highlights how distinctions between impairment and disability evolved within this perspective, but also how definitions of impairment and disability remain contentious. It discusses how revisions within the disability rights' perspective have emphasised the importance of the impact of impairment together with disability. The chapter then highlights how debates on disability and impairment have not been extended to people with learning disabilities, though relevant to them. It demonstrates the extent to which physical health conditions are experienced by the learning disability population, and argues that physical as well as cognitive impairments affect people with learning disabilities. These combined with disabilist circumstances revealed within the chapter, impact on the health of this group of men. The chapter concludes that work on disability and health more generally has also not drawn on the perspectives of men with learning disabilities.

Chapter 3 The significance of relative poverty for the health of men with learning disabilities

Chapter three reviews the patterns of health inequalities in the UK and their

association with relative poverty. The chapter then moves on to discuss the different explanations put forward to account for such health inequalities. It explores the evidence and association of socio-economic disadvantage and poorer health chances in general. It then analyses the existing evidence related to socio-economic disadvantage and people with learning disabilities, with reference to income disadvantage for adults with learning disabilities. The chapter then discusses the implications this has for undermining both the physical and mental health of people with learning disabilities. Finally, the chapter highlights how despite its significance, the impact of relative poverty on their health has not been explored from the perspective of men with learning disabilities in any substantive way.

Chapter 4 The significance of gender for the health of men with learning disabilities

This chapter begins by reviewing key evidence on the patterns of men's health in the United Kingdom. It then considers the perspectives offered by the sociology of masculinity, on the nature of men's experience of gender, with particular reference to the model of *hegemonic masculinity,* as proposed by Connell *(1995).* The chapter discusses how, whilst this model has been influential in promoting research in this area, more recent debates on masculinity recognise that there are multiple forms of masculinity, or masculinities, and acknowledge the different ways in which men 'practice' masculinities in their every-day lives. The chapter then reviews how studies have drawn on such concepts to help promote greater understanding of the

gendered nature of men's experience and perceptions of health, including the undermining effects of adherence to masculine ideals. The chapter highlights how, nevertheless, little evidence exists that explores how men with learning disabilities construct masculinity, and its impact on their health. The chapter concludes that gender needs to be explored as a further key social dimension that has the potential to impact on this group of men's health in their daily lives.

Chapter 5 Methodology employed in the empirical study of the perspectives and experiences of men with learning disabilities

This chapter sets out the perspectives that have influenced the design of the research, with its focus on men's accounts setting out their experience and perspectives. It reviews how key elements of the research methodology were aligned to a participatory approach. This included men's participation as steering group members across the research process, as well as interview participants. Here a qualitative approach to interviewing was employed, to gain an in-depth understanding of participants' viewpoints and experience. The steps undertaken to develop a relationship with the men, in order to maximise their involvement, together with measures to make engagement in the research process accessible, are discussed in detail. The role of practitioner as researcher, the method of analysis employed, modes of dissemination and limitations to the research are then analysed.

Chapter 6 How men with learning disabilities perceive and experience the impact of disability on their health

Chapter six is the first of three chapters that present the data analysis from the empirical study. It analyses the varied ways in which the men understand and experience disability impacting on their health. It highlights new insights into men's awareness of their health problems, and health promoting behaviour, and how while relationships with their primary care providers can be positive, disabilist aspects of health care still feature. It also indicates how disability related victimisation has an impact on the men's physical and psychological well being. Finally, the men's accounts highlight how they value friendship with both men with and without learning disabilities and its benefits for their psychological health.

Chapter 7 How men with learning disabilities perceive and experience the impact of relative poverty on their health

In this chapter, income, employment and neighbourhoods feature as key aspects to how the men perceive relative poverty impacting on their health. The chapter also demonstrates how men's experience of relative poverty varies. For example, comprehensive caring arrangements shielded some men from awareness of low levels of income, although such arrangements are not unproblematic. Men living more independently, as advocated in current policy and practice, were acutely aware of having to survive on very little income, associated with poor employment opportunities, and the impact this had on their health. Employment was not uniformly linked to

improvements in psychological health, some men were happy to be without work, while others found their poor employment chances were undermining. It also highlights men's awareness of how their learning disability related health conditions impact negatively on their employment situation. Findings also highlight men's awareness of personal threats to physical safety and psychological wellbeing, associated with living in deprived neighbourhoods.

Chapter 8 How men with learning disabilities perceive and experience the impact of masculinity on their health

This chapter presents the main findings related to how gender impacts on the health of the men. It first highlights new insights into how the men understand and express masculinity. These reflect traditional male practices, in terms of protector/provider roles. The men also show an awareness of how masculinity can be constructed in the workplace, referring to undertaking physically demanding work and its effects on their health. However, the men's accounts reveal how they may move on to value taking responsibility for their own health. The men reveal as well, their marginalised position regarding other men, as in their sense of vulnerability when drinking in public, and other situations where they feel dominated by other men. Overall, the analysis shows how this particular group of men have the capacity to understand a range of ways in which masculine ideas and behaviour can impact on their health, and construct masculinity in different ways impacting on their health.

Chapter 9 Conclusions

This chapter synthesises the main findings of the thesis. It distils the key features of the men's experience and perceptions of the impact of the social divisions of disability, relative poverty, and gender on their health. It also highlights the benefits of adopting a theoretical approach which explores these three key dimensions to reveal new insights into their effects on the health of men with learning disabilities. The conclusions also indicate how taking account of the interplay between the social divisions - as in the combined effects of disability related victimisation, together with threats to physical safety within deprived neighbourhoods, and marginalised masculine identity - reveals how this can impact adversely on the health status of this group of men.

Grounding the research in the perceptions and experiences of the men is shown to have illuminated insights that otherwise would not have been known, with implications for future, research policy and practice.

Chapter Two

The significance of disability for the health of men with learning disabilities

Introduction

This chapter will review existing literature that contributes to understanding the significance of disability for the health of men with learning disabilities. The chapter begins by discussing medical understandings of disability and the definitions of impairment these incorporated. It then explores how the disability rights perspective originated in opposition to the medical model of disability, and has put forward what has become known as the social model of disability. This has emphasised how disabling social structures and circumstances are the main causes of oppression for disabled people. The chapter moves on to review how debates on disability and impairment have developed, with new theoretical understandings of the importance of impairment alongside disability being developed within a disability rights perspective. It then charts the position of people with learning disabilities' within these debates within the UK and highlights the injustice of their exclusion. It shows how people with learning disabilities are grappling with impairment in the form of physical health conditions, associated with cognitive impairment, together with the negative effects of disabilist mainstream health care and victimisation in wider society. The chapter concludes that both impairment and disability have a significant impact on the health of men with learning disabilities and argues it is important to

deepen our understanding of their effects on health, by gaining first-hand accounts from the men themselves.

Medical understandings of disability

Prior to the 1970s, medical understandings of disability were dominant in theory and practice relating to the issue. The power and dominance of the medical profession (Freidson, 1970), together with the Victorian enthusiasm to classify and 'medicalise' people, had resulted in many disabled people being 'housed' in long stay institutions (Craft, 1985). Thus, the solution to overcoming disability was predominantly seen as lying through medical diagnosis and treatment (Barnes et al, 1999). According to the medical model of disability, disabled people were defined by their illness or condition and the medical treatment related to it (Barnes et al, 1999). Once people had been medically categorised in this way, their disability became their defining characteristic. The main aim of the medical model was to diagnose and treat aspects of the individual's impairment, which comprised of different physical, psychological, cognitive conditions, or accidental injury, such as loss of limb, and then provide a range of different rehabilitative and professional interventions to help them adjust, or where possible, recover (Barnes, 2002).

This formed the basis for an individualistic approach, which regarded the person as a victim (Oliver, 1983). Within this understanding of disability:

Individuals are socialised into a traditional disabled role and identity and are expected to submit to professional intervention to facilitate their adjustment to their personal tragedy

(Barnes et al, 1999:26).

As is clear from this extract, within the medical model, disability was seen as an individual problem, which inflicted damage on the mind and/or the body and that was perceived to need treatment and possibly, potential cure (Goodley, 2011).

Accompanying medical understandings of disability was a systematic approach to assessing and measuring a disabled person's individual functional ability, to determine the level of service a disabled person might require. The World Health Organisation (WHO) was influential in this debate, defining impairment, disability and handicap in the following ways:

Impairment *was any loss or abnormality of psychological, physiological, or anatomical structure or function'...***disability** *was any restriction or lack of ability, resulting from impairment, to perform an activity in the manner or within the range considered normal for a human being ...***handicap** *was a disadvantage for a given individual, resulting from an impairment*

or disability, that limits or prevents the fulfilment of a role

(WHO, 1980:27).

Historically, medical assumptions concerning the situation of people with learning disabilities required their cognitive deficits to be assessed and categorised and in so doing constructed this population as a medical problem (McClimens 2005). According to McClimens (2005), the knowledge, power and language of the medical profession, created the circumstances that determined how people with learning disabilities were treated as separate from the population who were not disabled in this way.

The crux of the medical model therefore, was that it did not acknowledge how social barriers, or conditions within society might be altered to meet the needs of disabled people, and up until the 1970s the public perception of disabled people aligned itself with this 'medical model' (Thomas, 1982).

Social understandings of disability: The emergence of the disability rights perspective

The disability rights perspective emerged in direct opposition to the medical model of disability. During the 1970s the medical model of disability came under increasing criticism, as disabled activists and their organisations argued that it was society that disabled people with impairments (Oliver, 1983). The disability rights perspective was concerned with establishing

equal rights for disabled people that were related to areas such as independent living, access to equitable health services and the need to challenge the relationship between impairment and disability (Danieli and Wheeler, 2006). The concept of rights, justice and citizenship were increasingly articulated as both the basis for disabled people's claims to support and services, and more generally, to evoke the necessary changes to wider social environments, structures and laws (Stainton, 2002). These factors were seen as preventing disabled people from exercising their rights on an equal basis to non-disabled people (Stainton, 2002). As promoted by the disability movement, any meaningful solution had to involve societal change rather than simply individual adjustment and rehabilitation.

Embedded in the perspectives developed by the disability movement of the 1970s, what has come to be known as the social model of disability came into existence (Thomas, 2007). A key aspect of the social model is that it shifts attention away from the individual's physical, psychological or intellectual impairments, to the way that society either includes or excludes disabled people (Shakespeare, 2006).This model concentrates on a set of socially constructed causes and obstacles that are imposed on disabled people that limit their opportunities to participate in society (Oliver, 1986). Within the disability rights perspective, the distinction between impairment and disability was conceptualised, as disabled activists sought to establish the idea that impairment was no longer the cause of disability (Thomas, 2007). The Union of the Physically Impaired Against Segregation (UPIAS), distinguished between impairment and disability in the following terms:

*We define **impairment** as lacking part or all of the limb, or having a defective limb, organ or mechanism of the body; and **disability** as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression*

(UPIAS, 1976:14).

Disability activists, through what is known as the social model approach, have been successful in various ways, which has lead to legislative change. This has been achieved through a range of initiatives including direct action, lobbying governments, protests rejecting residential forms of care and the promotion of centres for independent living, which have been run and controlled by disabled people (Barnes and Mercer, 2006). Legislative changes in the UK can be traced back to the *Commission of Restrictions Against Disabled People* (CORAD) in 1982, which culminated in the Disability Discrimination Act (1995). The formation of the Disability Rights Commission was formed in the 1990s and legislative change has recently resulted in the Equalities Act (2010). Despite the persistence of forms of discrimination, these have made a positive difference to the lives of many disabled people (Barnes, 2002). For example, in the United Kingdom, organisational changes have been facilitated through introduction of equality training and the promotion of more inclusive forms of education for disabled

people (Barnes, 2002). Furthermore, the disability movement has been

successful in promoting disability as a form of socially constructed

oppression, allowing disabilism to gain recognition in public consciousness

and debate, together with other forms of oppression, such as racism and

sexism (Goodley, 2011).

Alongside the wider disability movement, people with learning disabilities

were beginning to have a say on issues that mattered to them. This can be

charted through the development of the self advocacy movement (Craft,

1985). The *People First* organisation was an umbrella organisation for self

advocacy groups for people with learning disabilities, which was developed

in the late 1970s and early 1980s across the UK and North America

(Brechin and Walmsley, 1989). Self advocacy groups have enabled people

with learning disabilities to speak up for themselves on a number of topics

that affected their lives, such as changes to day centre provision (Brechin

and Walmsley, 1989). The number of self advocacy groups for people with

learning disabilities has increased substantially in the United Kingdom over

the last twenty five years (Beart, 2005) and such endeavours have been

financially supported by government policy (DH, 2001).

However, exclusionary tendencies concerning people with learning

disabilities have been reported within the disability movement itself. For

example, some have argued that the voices of people with cognitive

impairments have been marginalised (Richardson, 2005). The notion that

people with learning disabilities are not included in the wider disabled

movement is illustrated by the following comment on this issue from a

woman with learning disabilities herself:

People without learning disabilities use the medical model when dealing

with us. We are always asked to talk about advocacy and our

impairments as though _our barriers aren't disabling in the same way as_

disabled people without learning disabilities. [Own emphasis] *We want*

concentration on our access into the mainstream disability movement

(Simone Aspis of London People First in Campbell and Oliver, 1996:97).

Revisions within the disability perspective: disability and impairment.

Despite the success with which the social model of disability has enabled

disabled people to promote their political and economic rights (Abberley,

1987), on a theoretical level the model has also received criticism from

within the disability rights perspective itself (e.g. Morris 1991 and Crow,

1996; Thomas, 2004; Shakespeare, 2006). This section shows how

theoretical revisions from writers on disability have led to impairment being

viewed as important alongside disability. A number of disability theorists

have questioned the assumptions that have underpinned the social model of

disability. This criticism takes two forms. Firstly, it has been recognised that

when researching the experiences of disabled people, it is very difficult to

distinguish between the relevance of impairment and disability and how

these two aspects together, affect the lives of disabled people (Shakespeare, 2006). Shakespeare and Watson (2001) claim the social model of disability over-asserts how impairment and disability are separated and that impairment does play a role in causing disability:

People are disabled by both social barriers and by their bodies. This is uncontroversial. The British social model of disability, because it 'over – eggs the pudding', risks discrediting the entire dish.

(Shakespeare and Watson 2001:17).

Shakespeare has expressed this point in even sharper terms: 'There can be no impairment without disability or disability without impairment', (Shakespeare, 2006:21). Secondly, the social model defines disability exclusively in terms of oppression and social barriers and as such it provides little place for how impairment may impact on the lives of disabled people. Theorists seeking to revise social understandings of disability have sought to refocus attention on impairment (Crow, 1996; Hughes and Paterson, 1997), in what has been referred to as a 'turn to impairment' (Goodley, 2001:208). Disability theorists, who have argued to bring impairment back to the forefront of analysis (Crow, 1996; Hughes and Paterson, 1997), are not attempting to reinstate medical model understandings of impairment, but to draw attention to the significance of impairment alongside disability. Morris (1991), a feminist writer, pointedly

acknowledged the pain and difficulties associated with the impairment itself,

which could not be specifically attributed to disabling social factors:

While environmental barriers and social attitudes are a crucial part of our

experience of disability and do indeed disable us, to suggest that this is

all there is, is to deny the personal experiences of physical and

intellectual restrictions, of illness, and of the fear of dying.

(Morris, 1991:10).

From a similar standpoint, Crow, a disabled feminist writer, called for greater

acknowledgment of the integral experience of impairment for disabled

people, in order to help combat disability. Crow argues that:

What we need is to find a way to integrate impairment into our whole

experience and sense of ourselves for the sake of own physical and

emotional well being, and subsequently, for our individual and collective

capacity to work against disability

(Crow,1996:54).

In a similar vein, work by Thomas (2004a; 2004b) calls for the personal

experience of disabled people to be acknowledged, by recognising that

impairments do have direct and restricting impacts on the social lives of

disabled people. However, reverting back to the understanding of disability provided by Finkelstein (1980), Thomas (2004b) also argues that the 'social relational' character of disability (how the relationship between disabled and non-disabled people is played out), is a form of social oppression. This is associated with relationships at both a macro and micro level between people with and without impairments (Thomas, 2004b). Hughes and Goodley have argued along similar lines, while substituting 'culture' for 'society' .They suggest that impairment is an embodied experience that is influenced and shaped by culture (Hughes, 2002; Goodley, 2001). This standpoint is echoed in the most recent World Health Report on disability (WHO, 2011):

Disability is a complex, dynamic, multi-dimensional concept that engages both intrinsic features of human physiology and functioning, the domain of health and features of the physical, human built, social and attitudinal environment

(WHO, 2011:3).

Oliver a leading proponent of the social model of disability in the UK has recently claimed that the social model of disability does not negate questions and concerns related to impairment and/or the importance of medical interventions. Rather, Oliver (2009) argues that the difficulty for many disabled people is in coming to terms with the consequences of impairments in a disabilist society:

Coming to terms with the consequences of impairment in a society that devalues disabled people and disabled lifestyles is the personal tragedy. But the real misfortune is that our society continues to discriminate, exclude and oppress people with impairments

(Oliver, 2009:47).

Drawing on the critique represented by these writers suggests that to understand the experience of disabled people therefore, requires an approach that acknowledges the consequences of <u>both</u> impairment and disability. This should not be as ill-defined as being portrayed as simply 'on a continuum', but recognises the interplay between impairment and disability and its impact (Shakespeare and Watson, 2001). If individuals have to live with both impairment and disability then both contribute to the experience of disability at a personal level (Hughes et al, 2005).

Disability: impairment, and people with learning disabilities

Charting the position of people with learning disabilities within these theoretical debates, it is clear that limited research has explored how people with learning disabilities view how disabling barriers and their impairments, impact on their physical health and psychological well-being. Theoretical studies on disabled people tend to discuss these issues in more general terms, making reference to the broader disabled population, without seeking

different representations from smaller groups of people, such as people with learning disabilities (Corker, 1999).

Goodley (2001) argues it has been a challenge for disability theorists to make theoretical discussions applicable to this group of people and to acknowledge their activism through the self advocacy movement. The exclusion of people with learning disabilities from within such debates has been attributed, in part, to the influential definition put forward by UPIAS (1976), which separates impairment and disability. Goodley (2001:31) argues that employing this definition has risked simply conceptualising learning disability as an 'organic **impairment** [own emphasis] of intellectual functioning'. Chappell et al (2001) claim that conceptualising learning disability in this way has meant that people with learning disabilities have been excluded from debates concerning the social model of disability. Chappell et al (2001:46) go on to argue that 'it seems as if there is a divide between people with physical and sensory impairments and those with learning disabilities'. That said, it is the case that the voices of women with learning disabilities have begun to be heard in relation to their experiences of the impact of disability (Women's First Group cited in Cohen and Mullender, 2003). These perspectives from learning disabled women have been promoted primarily by writers from a feminist standpoint (Morris, 1991; Graham, 1992; Thomas, 2004a; 2004b):

Perhaps the hardest inequalities to tackle within our group were those based around perceived levels of disablement. The doctors and other professionals who took disabled people over and made them 'specialist territory' had split us into so many types and categories that we forgot what we had in common politically (Women's First Group, 2003:125).

However, despite these contributions from feminist writers (Corker, 1999), theoretical debates have not focused on the situation of men with learning disabilities' experience of impairment and disability and its impact on health.

Goodley and Boxall (2002) are amongst the few disability theorists who have attempted to develop analysis centred on the relevance of the social model of disability to people with learning disabilities (Goodley, 2001). In their analysis, within a social model, discourses have promoted learning disability as a social, cultural, historical and relational phenomenon (Goodley, 2001:5). In addition, a social model has been drawn on in attempts to enable people with learning disabilities to take full control of their lives and overcome the barriers put in their way, due to their learning disability (Race et al, 2005). Similarly, Watson (2002) argues that a significant body of social science literature goes back to the 1960s, which has explored 'learning disability' as a social creation of a disabling society. This debate originated three decades ago, when Bogdan and Taylor (1982) drew a number of conclusions regarding how learning disability is socially determined:

If there is one firm conclusion to be made…it is that mild mental

retardation is as much or more a social and cultural phenomenon as it is

a medical, genetic, cognitive and psychological one. The definition, then

of some of the consequences of being thus labelled are concomitants of

social life (cited in Levine and Langness, 1986:191).

Although this comment clearly places emphasis on learning disability being

socially constructed, there has been limited reference to the significance of

impairment and people with learning disabilities. For people with learning

disabilities, any discussion of impairment has been restricted to discussions

of 'mental' impairments (Goodley, 2001). Some work by Fairclough (1992)

identified how such labels can limit the state of knowledge in different fields.

In the case of people with learning disabilities, terms such as syndromes

and 'mental impairments' have been freely applied, which tend to convey

negative assumptions regarding the cognitive impairments of this group of

people (Fairclough, 1992). Moreover, this standpoint does not take account

of the evidence base of specific physical health issues experienced by

people with learning disabilities (Emerson and Baines, 2010). It sidesteps

the impact that physical conditions associated with learning disability can

have on wellbeing and the health requirements of this group of people.

The chapter so far has highlighted how there is a lack of literature that takes

account of the distinctive physical impairments of men with learning

disabilities, together with their experience of social discrimination and

disadvantage (DRC, 2006). To date, disability studies have also sidelined the views of people with learning disabilities themselves regarding the impact of disability and impairment on their health. This is regrettable, as the dual focus within the disability rights perspective on the demands of disability and impairments is very significant to people with learning disabilities, as the next section will demonstrate.

Impairment, disability and the health of people with learning disabilities

Impairment: physical health conditions associated with cognitive impairment

People with learning disabilities have poorer physical health than non-disabled people, as a consequence of physical health conditions associated with cognitive impairment (Emerson and Baines, 2010). They have an increased risk of physical health conditions associated with specific genetic and biological causes of learning disability, such as congenital heart disease among people with Down's syndrome (Roizen and Patterson, 2003).

Coronary heart disease has been reported as affecting people with learning disabilities more frequently than the general population and is a significant cause of death for people with Down's syndrome (Bittles et al, 2007). Other congenital disorders also have physical health problems, which are specifically related to the disorder. The disorder Fragile X, for example, has a spectrum of physical, intellectual, emotional and behavioural features and

Prader Willi Syndrome, is associated with impaired movement and higher rates of obesity (Lantman-de Valk, 2005).

A further range of serious health conditions are associated with learning disability. Respiratory illness, for example, is the main cause of death amongst all people with learning disabilities (Tyrer and McGrother, 2009). Sensory impairments concerning sight and hearing are common amongst this population. Amongst adults, the prevalence of visual impairment increases with the severity of the learning disability. A literature review by Warburg (2001) found people with learning disabilities to be between 8.5 and 20 times more likely to have a visual impairment than the general population. Evenhuis et al (2001) found that 21 per cent of people with learning disabilities in residential settings had hearing impairment. Emerson and Baines (2010) have reported that between 25 per cent and 40 per cent of people with learning disabilities having hearing impairment. Epilepsy as a condition occurs fifteen to thirty times as often in this group of people, compared with the general population (Espie et al, 2003). There is also an association between epilepsy and psychiatric conditions and behavioural difficulties, which all affect the quality of life of people with learning disabilities (Mathews et al, 2008).

As indicated in chapter one, this study focuses primarily on the experience of physical health conditions and the disabling circumstances that can impact on the physical health of men with learning disabilities. Therefore,

mental health issues are not a central focus of the empirical study. However, it is important to note that people with learning disabilities have a high risk of developing additional mental health problems, compared with the general population (Cooper et al, 2007). Moreover, as discussed in the following section, these problems often go unrecognised which has a major effect on people's well being, personal independence and quality of life (Raghuvan and Patel, 2005).

The life expectancy of people with learning disabilities is increasing, as in the general population (Houghton et al, 2012), However, the life expectancy of people with learning disabilities, as a total population, remains shorter than that of the general population, and is reduced for those with more severe learning disabilities to as low as 54 years (Roy et al, 2006). Some researchers have argued that this can be attributed to the increased risk associated with the earlier onset of disorders such as dementia (Bittles et al, 2007). Nevertheless, Houghton et al (2012) have cited evidence implicating the effects of inferior social conditions and healthcare, in showing that the incidence of deaths from preventable causes amongst the learning disabled population is three times higher than among the general population.

Disabilist acute and primary healthcare: negative impact on health

In addition to grappling with the impact of impairment on physical well-being, people with learning disabilities experience negative consequences for their physical health as a result of disabilist attitudes and practices within acute

health care and primary care. At the time of writing, *the Winterbourne Interim Report* (DH, 2012a) has concluded that people with learning disabilities have experienced extreme and unacceptable forms of abuse, whilst living in independent residential health care provision, and not just confined to a few residential settings. While this is a cause for serious concern in its own right, the focus of this thesis is not on experience of residential care. Nevertheless, the report also revealed limitations in the assessment and inspection standards of health and social care provided by the Care Quality Commission, which are relevant to health and social care settings across the board. A number of measures have been put in place to address these shortcomings, with further planned inspections of one hundred and fifty services for people with learning disabilities (DH, 2012a).

Within the acute health care sector, examples of discrimination against people with learning disabilities have been reported. The '*Death by Indifference'* report (Mencap, 2007a) demonstrated how individuals with learning disabilities experienced disabilist treatment. A number of case studies within the report highlighted incidents where individual medical professionals had a poor understanding of how to treat people with learning disabilities in acute care and how basic forms of treatments were denied these individuals (Mencap, 2007a). The '*Health Care for All'* report (Michael 2008) investigated the cases identified within this report and highlighted that people with learning disabilities faced unnecessary suffering. The cases highlighted how people with learning disabilities were denied basic pain relief and that avoidable deaths occurred. This report also highlighted how

specific laws that should guide health professional practice, such as the Human Rights Act (1998) and the Mental Capacity Act (2005), were not followed. The subsequent report, *'Six Lives: The provision of public services to people with learning disabilities'* (Abraham and White, 2009), showed how basic hospital policy and guidance had not been adhered to and the needs of this group of people had not been met. In the specific case of Mr Ryan, the parliamentary ombudsman reported:

No explanations were found to explain why Mr Ryan died of a stroke at such a young age…The NHS Trust failed to meet his basics needs, failing to feed him for twenty six days after he suffered a stroke.

(Abraham and White, 2009:25)

In another case, the out of hours GP service stated that Mr Cox's fever, raised blood pressure and grossly swollen abdomen required urgent admission to hospital. On arrival at the hospital, the report (2009) stated:

Mr Cox's health deteriorated rapidly, but the medical investigations at that time were reported as normal. Mr Cox's ruptured appendix was misdiagnosed on admission to hospital and he died an hour and a half later.

(Abraham and White, 2009:46)

Abraham and White (2009) concluded Mr Cox was treated less favourably on the grounds of his disability.

Since the Michael Report (2008), an interim Confidential Inquiry Team has been established to identify the contributing factors into the unnecessary deaths of people with learning disabilities in acute care (Heslop and Marriott, 2011). Hatton et al (2011) conducted a national survey of reasonable adjustments made by NHS Trusts in England, regarding people with learning disabilities. The survey highlighted that whilst many NHS Trusts were attempting to make reasonable adjustments, with for example, the production of accessible information, further improvements were required to provide an adequate standard of provision (Hatton et al, 2011). There is also emerging evidence that the end of life and palliative care needs of people with learning disabilities are not met (Tuffrey-Wijne et al, 2007). Examples to illustrate this include inadequate pain and symptom management and a lack service planning for people with learning disabilities with palliative care needs (Tuffrey-Wijne et al, 2007).

In addition to the necessity for health monitoring of conditions associated with learning disability, such as cardiac difficulties, this population also experience the same general health conditions as the non-disabled population, such as asthma and diabetes which also require monitoring (DH, 2001). Accessing regular health monitoring within primary health care for many people with learning disabilities, however, can also be problematic

(Kerr et al, 1996; Martin et al, 2005). Primary health care services in general rely on individuals to be able to detect symptoms, access written materials and communicate their needs, all of which can be problematic for people with learning disabilities (Pehl and Hunt, 2004). However, whether they receive the necessary health promotion provision, to assist with effective monitoring and treatment of such general health conditions, to fully meet their needs, is difficult to assess (Martin et al, 2005). The DRC (2006), report '*Closing the gap: Equal treatment'* highlighted incidences where people with learning disabilities had not received equitable primary health care. This report found that this group of people were disadvantaged and denied basic forms of health monitoring and health promotion activities when compared with the general population within primary care (DRC, 2006). This resulted in calls for more annual health reviews for people with learning disabilities within primary care (DH, 2007), which can identify previously undiagnosed health conditions (Chauhan et al, 2010). The '*Six Lives Progress Report'* (DH, 2010) has highlighted that there has been an increase in annual health reviews within primary health care for people with learning disabilities. However, there is still a notable variation in the uptake of health reviews across England (Houghton et al, 2012). Moreover, only fifty three per cent of people with learning disabilities received an annual health review in England in the last year (Emerson et al 2011). Despite the evidence of additional health conditions present within this population, alongside general health conditions (Emerson and Baines, 2010), the indications are that this group of people are therefore still receiving inferior preventative primary health care.

Attempts have been made by a specialized learning disability nursing workforce to overcome the challenges this group of people can present primary care (DH, 2012b). Amongst the total of 655,935 nurses in the UK, there are 21,123 registered learning disability nurses (Nursing and Midwifery Council, 2011). This small specialised nursing workforce undertaking health promotion activity with people with learning disabilities is recorded as having made progress in promoting awareness of their needs and supporting health reviews in primary care (Taggart et al, 2011). However, this minority workforce does not have the capacity to support primary care, to meet the needs of all people with learning disabilities registered with their practices, as reflected in annual health checks still not being the norm.

Further forms of disabilist health care are experienced by people with learning disabilities. There is evidence that people with learning disabilities experience 'diagnostic overshadowing' where the detection and significance of physical and mental health difficulties are primarily accounted for by the presence of learning disability. This further compounds their disadvantaged position. As a result of having a learning disability, other forms of ill-health can go undetected, such as hypothyroidism (under active thyroid) and depression (Raghuvan and Patel, 2005).

Additional dimensions to disadvantage regarding health care have been reported amongst people with learning disabilities from minority ethnic communities, who often face exclusion and isolation regarding their physical

or mental health problems, resulting in "double disadvantage" (Poxton et al, 2012). People with learning disabilities from minority ethnic groups have also been found to face barriers in their access to statutory support services (Chamba et al, 1999). This includes a lack of ethnically sensitive respite care services (Poxton et al, 2012).

Gendered dimensions to disadvantage in health care

Examples of good practice which outline specific health promotion measures aimed at learning disabled women are reflected in the document '*Equal Access to Breast and Cervical Screening for Disabled Women'* (National Health Service Cancer Screening Programmes 2006). However, despite the merits of such a document, the same consideration has not been afforded to men with learning disabilities (Peate and Maloret, 2007). While the incidence of cancer appears to be increasing amongst people with learning disabilities (O'Regan and Drummond, 2008), in relation to cancer services, men with learning disabilities appear to be disadvantaged when compared with women with learning disabilities at a national level (Peate and Maloret, 2007). As part of the *NHS Cancer Plan, a plan for investment, a plan for reform* (Department of Health, 2000) women with learning disabilities were consulted to help draw up cervical screening and breast awareness guidelines. However, this document did not include men with learning disabilities in the formulation of good practice in relation to areas such as testicular self examination (Peate and Maloret, 2007).

Moreover, men in general appear more reluctant to seek out health professional advice and have been documented as more likely to engage in health damaging behaviours (O'Brien et al, 2009). A systematic review of the literature has indicated that there is no empirical evidence related to whether men with learning disabilities are reluctant to seek out health advice, or how, from their own perspective, they behave in relation to their health. This lack of knowledge, if left unexplored, alongside the discriminatory attitudes towards people with learning disabilities within mainstream health care (Michael, 2008; Abraham and White, 2009), and the known higher incidence of specific health conditions associated with learning disability (Emerson and Baines, 2010), potentially compounds the health risks for men with learning disabilities. Yet the full impact of this situation remains unknown.

People with learning disabilities through the forms of impairment associated with learning disability therefore, experience specific as well as general health needs. The incidence of learning disability is higher among men than women. In some respects specific genetic disorders, such as Fragile X syndrome affect males with learning disabilities more than women with learning disabilities (Brock and Hatton, 2010). Men with Fragile X are also more likely to be affected by autism than females (Clifford et al, 2007). There are also indications of higher mortality rates amongst men with learning disabilities in certain diseases, such as within the digestive system and respiratory infections (Patja et al, 2001). This, together with evidence of disabilist tendencies within secondary health care and possibly even more

sparse access to health screening and health promotion activities, within primary health care, constitutes a serious danger to the health of men with learning disabilities.

Disabilist employment opportunities and health

An example of disabilist social disadvantage concerning the health of men with learning disabilities in wider society, relates to the impact of reduced employment chances on health. Previous work on employment and health in general shows how employment is positively linked to good physical and mental health and that the health of men and women is improved through employment (Ross and Mirowsky, 1995). There is also significant evidence related to the negative effects on physical and mental health associated with unemployment (Dorling, 2009). Other marginalised groups, such as those with mental health issues, have reported the challenges of coping with a mental health problem and maintaining employment (Department of Work and Pensions, 2008). Similarly, people with learning disabilities experience more mental health difficulties compared with the general population, in addition to the cognitive difficulties associated with learning disability (Cooper et al, 2007). Moreover, research has shown that the communication difficulties, physical and mental health conditions of people with learning disabilities are assumed by others to have a detrimental impact on their capacity for employment (McConkey and Mezza, 2001). Less than ten per cent of people with learning disabilities are in paid employment (DH, 2009). Local authority schemes, for example 'Supported Employment' established

to sustain employment opportunities for people with learning disabilities are not universally available (Beyer et al, 2010). These conditions, therefore, reduce the chances of improved health benefits for men with learning disabilities, gained from participating in full time and sustained employment (Ross and Mirowsky, 1995). However, there is a lack of evidence regarding the views of people with learning disabilities on the effects of problematic employment opportunities on their health (McConkey and Mezza, 2001). As people with learning disabilities are more likely to have restricted employment opportunities, to be more reliant on welfare benefits and at risk of long term unemployment (Emerson, 2005), they are more likely to be on low incomes. The association between low income and inferior health is well documented (Lynch et al, 2000), and the implications of this for men with learning disabilities, will be examined in the next chapter.

Disabilist victimisation and health

Degrading conditions and the abuse of people with learning disabilities were revealed to have taken place within 'long-stay' institutions in the 1960s and 1970s (Department of Health and Social Security, 1969; 1971). The advent of Community Care policy and legislation (Braddock et al, 2001), instigated measures to move people with learning disabilities away from the segregated living circumstances of 'long-stay' institutions, which had been sites of victimisation and abuse. However, this policy shift has not necessarily guaranteed a safer or more inclusive life for people with learning disabilities (Fryson at al, 2004). Although the context of care delivery has

changed to smaller living dwellings and more independent living options (Manthorpe et al, 2009), bullying and hostile actions from neighbours and other members of the public, towards people with learning disabilities, have been reported (DRC, 2004; Mencap, 2007b). Examples of this include people with learning disabilities being kicked and punched by their neighbours and young people causing injury by throwing stones (Mencap, 2007b). A number of high profile cases where individuals with learning disabilities have been persistently victimised have revealed the vulnerability of this group of people, in particular those living by themselves without an obvious social network (Quarmby, 2011). However, there is an absence of first hand evidence from men with learning disabilities themselves, on their experience of the impact this has on their physical health and psychological well being.

Conclusion

This chapter has reviewed the impact of disability on the health of men with learning disabilities. Medical understandings of disability have been shown to have emphasised the restrictive effects of impairment. The chapter has then discussed how writers from the disability rights movement, opposing this medical standpoint, have argued that disabilist social barriers affect the lives of disabled people more profoundly and have foregrounded and promoted this argument via the social model of disability (Oliver, 1996, 2009; Barnes and Mercer, 1999).

The chapter has then explored how subsequently writers from within a disability rights perspective have contended that living with the demands of impairment, for example, psychological, cognitive, and physical conditions - the 'impairment effects', together with disabling social circumstances, contribute to the experience of disability (Hughes et al, 2005). Yet, as Goodley, (2001; 2011) has argued, this theoretical discussion has not been developed in relation to people with learning disabilities. This chapter has illustrated how men with learning disabilities have to grapple **both** with the effects of physical conditions associated with cognitive impairment and disabilist treatment, to the detriment of their health.

Social oppression, a cornerstone of the disability rights perspective, is difficult to deny when considering men with learning disabilities' experience of health care. Disadvantageous employment conditions and instances of victimisation provide a stark representation of the marginalised position this group of people hold in contemporary society. This, together with the evidence of physical health conditions as a constituent of impairment in this population, needs to be understood more fully, as it is integral to the experience of health on the part of men with learning disabilities. This thesis intends to 'open up' these issues with men with learning disabilities. Through eliciting their accounts regarding the impact of disability and impairment on their health, it intends to enrich current analysis and provide a basis for future research.

Chapter 3

The significance of relative poverty for the health of

men with learning disabilities

Introduction

This chapter will consider the literature related to relative poverty and the health of men with learning disabilities. It begins by discussing evidence of the association between socio-economic disadvantage and poorer health chances in general. It reveals how life expectancy and patterns of ill health continue to vary according to socio-economic circumstances. It then considers the different explanations put forward for this, but emphasises that no single explanation can fully explain the multifaceted way in which advantage and disadvantage affect health. The chapter then moves on to review the evidence for the association between learning disability and socio-economic disadvantage. This shows how people with learning disabilities are more likely to experience social disadvantage and relative poverty than non-disabled people, particularly those people with less severe learning disabilities. The chapter then explores evidence that seeks to explain why people with learning disabilities are more likely to experience social disadvantage and relative poverty and the potential impact this can have on their health. The chapter concludes by suggesting that this evidence is relatively sparse and therefore this study seeks to add to evidence in this area through, the views and experiences of men with learning disabilities regarding how they understand the effects of relative poverty on their health.

Patterns of health inequalities in the general population

Patterns and trends regarding life expectancy and ill health change over time. For example, infectious diseases were the main cause of death in the 19th century. However, the association between an individual's social economic position and health remains persistent (Graham, 2009).There has been a great deal of research across the last three decades which has highlighted the differences in patterns of life expectancy and ill health between different socio-economic groups (Townsend and Davidson, 1982; Department of Health, 1998; Acheson Report 1998; Shaw et al, 1999; Department of Health, 2004). The Acheson Report (1998), for example, revealed unacceptable and avoidable health inequalities associated with socio-economic status at an individual, household and area level (Spencer and Dowling, 2009).

The evidence shows that mortality and morbidity follow a social gradient, with each step up the social hierarchy associated with a lower risk of ill health and premature death (Marmot, 2010). The evidence also shows that although life expectancy has increased across the population, the difference in life expectancy for men and women in different socio-economic groups has remained. For example, in 1972 life expectancy for men in social class five was 66 years compared to 73 years for men in social class one. In 2002, life expectancy for men in social class one was 80 years, compared to 72 years for men in social class five. For women, life expectancy rose from 78 years to 85 years for those in social class one, compared to an increase

from 74 years to 77 years for women in social class five (ONS, 2007). As discussed in chapter 2, the life expectancy of people with learning disabilities is increasing, bearing in mind the caveats highlighted.

Across the UK there is also evidence of inequalities in health between affluent and deprived areas. For example, in deprived areas such as Shettleston in Glasgow, three quarters of adult deaths occur before the age of 65 (Shaw et al, 1999). Differences in life expectancy are also evident within large cities. For example, there is a 10 year difference between a man living in the affluent borough of Westminster, compared to a man living in the more deprived area of Camden (DH, 2004).

The association between socio-economic circumstances and the incidence of diseases, such as cancer, coronary heart disease, stroke and Type Two diabetes have been well profiled (Marmot, 2004). For example, there are geographical differences in coronary heart disease (CHD) and stroke death rates between men living in less affluent areas in northern areas of England, compared with men living in more affluent southern areas (Morris et al, 2003). These show how CHD event rates vary from 6.16 per 1000 person-years in Guildford to 12.21 per 1000 person-years in Dewsbury. Similarly, stroke event rates vary from 2.00 per 1000 person-years in Guildford to 5.45 per 1000 person-years in Falkirk (Walker et al, 2000).

The evidence also shows that health inequalities exist at all stages of the lifecourse. The richer the family and community a child is born into the more healthy they are likely to be (Spencer, 2003). There are also disparities in infant mortality rates between different socio-economic groups, being 17 per cent higher in lower socio-economic groups (Ferguson et al, 2006). Differences in life expectancy between socio-economic groups continue into older adulthood. For example, the gap in life expectancy at 65 between the highest and lowest socio-economic groups was 3.5 years for men and 3.2 years for women (Marmot, 2010).

Explanations for inequalities in health

The difficulties regarding how we explain such inequalities in health have been highlighted by the World Health Organisation:

> *Health inequities are the result of a complex system operating at*
> *a global, national and local level which shapes the way society,*
> *at a national and a local level, organises its affairs and embodies*
> *different forms of social position and hierarchy. The place people*
> *occupy in the social hierarchy affects the level of exposure to*
> *health damaging factors, their vulnerability to ill health and the*
> *consequences of health (WHO, 2008:6).*

Explanations put forward to account for such inequalities in health not only

need to account for the differences between the affluent and the deprived,

but in addition must also explain the gradient in health that exists across the

social hierarchy (Graham, 2009). In line with traditional research within the

field of inequalities in health (Bartley, 2004), this chapter will now examine

the three main types of explanation put forward to account for health

inequalities. These are behavioural/cultural, materialist/neo-materialist and

psychosocial. Behavioural/cultural factors relate to differing

personal/culturally acceptable attitudes to health-related behaviours.

Materialist/neo-materialist explanations relate to conditions and exposures

faced by people in their home, community and workplace environments.

Psychosocial factors relate to the adverse psychological impact of stress

and low self-esteem.

Behavioural/ cultural explanations

Considerable attention has been paid to the possibility that differences in

damaging health-related behaviours are related to individual choices and

culturally accepted practices among groups of people (Shaw et al, 2007). In

particular, smoking, poor diet, lack of exercise and alcohol consumption,

result in inequalities in health (Wald and Nicolaides, 2008). In the UK rates

of cigarette smoking have declined across all socio-economic groups,

however the decline has been most notable in higher socio- economic

groups than lower socio-economic groups, with the result that a social

gradient amongst men and women has emerged and steepened over time

(Graham, 2009). For example, in 1958, sixty-one per cent of men in lower

socio-economic groups smoked, compared to forty-one per cent of men in

higher socio-economic groups in the same year. In 2000, thirty-nine per cent

of men in lower socio-economic groups continued to smoke, compared with

only fifteen per cent of men in higher socio-economic groups (ONS, 2001).

For women, forty one per cent of women in both high and lower socio-

economic groups smoked in 1958, which had reduced to thirty-five per cent

of women in lower socio-economic groups and fourteen per cent of women

in higher socio-economic groups in 2000 (ONS, 2001).

Given the negative impact of such behaviour on health, much of recent

governments' strategies to reduce inequalities on health and promote public

health, have centred on changing such health-related behaviour (DH, 2004;

2010). The *Wanless Report*, a government commissioned report

emphasised that while the circumstances in which people make health

decisions are complex, people require health information to take

responsibility for their health:

> *Individuals are ultimately responsible for their known and their children's*
>
> *health and it is the aggregate actions of individuals, which is ultimately*
>
> *responsible for whether or not such an optimistic scenario is fully*
>
> *engaged. People need to be supported more actively to make better*
>
> *decisions about their own health and welfare because there are*
>
> *widespread, systematic failures that influence the decisions individuals*
>
> *currently make* (DH, 2004: 4).

However, the validity of behavioural/cultural explanations remains contentious (Shaw et al, 2007). The evidence suggests that behavioural/cultural explanations alone cannot account for the social gradient in health (Mackenbach, 2006). Moreover, although the choices people make in relation to their health are often seen as the result of freewill, it is increasingly the case that research has taken into account the social context in which such choices are made, which highlight the social pressures and structural constraints underpinning such behaviour (Shaw et al, 2007; Blaxter, 2010). In short, it is increasingly recognised that such behaviours need to be contextualised in terms of people's material and psychosocial circumstances (Ridge and Wright, *2008).*

There is mounting evidence which identifies the crucial role of social disadvantage in constraining people's health-related behaviours. Shaw et al (2007) have shown that those in financial difficulties are those most likely to be disadvantaged regarding access to healthy nutritious food. Low income families, living in more deprived areas are disadvantaged in other ways, in relation to the affordability and accessibility of food and diet (Dowler, 1996). As such households may value the personal value of local shopping, given other limited social opportunities, food shopping can become a demoralising experience for those whose choice is restricted by a low income (Dowler, 1996).

Similar to diet, smoking should be considered as an outcome of social circumstances, not simply attributed to individual choice. Graham (1996)

showed that smoking can be a rational choice for women whose lives are constrained by lack of resources. Similarly, the benefits of exercise on individual health for those living in poor socio-economic positions, have been shown to be reduced by the material constraints associated with their socio-economic position (Blaxter, 2010).

More broadly, the World Health Organisation's Commission for Social Determinants and Health (2008), claim tackling inequalities in health requires overcoming the social determinants of health, which includes the political and economic structures that produce the inequities in people's lives. The influences of such determinants are seen to both directly and indirectly influence health inequalities, through health-related behaviours (Graham, 2009).

Materialist/neo-materialist explanations for health inequalities

Materialist explanations focus on the different material conditions and hazards that are inherent in society at an individual level, such as the direct effects of poor housing and working conditions (Williams et al, 2009). According to Shaw et al (1999) some individuals have no choice but to be exposed to such hazards, such as asthma, given the distribution of income and opportunity in society. However, such explanations although accounting for differences between the rich and poor, account less accurately for the reported gradients in mortality across society (Blane et al, 1998). In response, Williams et al (2009) claim more recently there has been growing

interest in the neo-materialist explanation, which has widened our understanding of this type of explanation. The neo-materialist explanation states that health inequalities result from the different accumulation of exposures and experiences that are based on various material sources, not only at the individual level, but also the community level (Lynch et al, 2000).

Neo-material explanations point to the systematic underinvestment across a wide range of physical, health and social infrastructures to account for inequalities in health (Kaplan et al, 1996; Lynch et al, 2000). These processes have an impact on the private resources available to individuals and shape the order of public infrastructure, such as education, health services, transportation, availability of food, quality of housing and occupational health regulations (Lynch et al, 2000).

Lifecourse explanation

Studies have shown that health in adulthood is the outcome of different socially patterned processes that can act across the entire lifecourse (Davey Smith et al, 1996; 1997). Principally based on longitudinal cohort studies, the lifecourse approach introduces a temporal examination of inequalities in health. This approach analyses how both advantage and disadvantage has been accumulated, attempting to trace the different factors and processes related to disease over time (Williams et al, 2009). For example, morbidity and mortality from respiratory disease in adulthood are related to education, housing conditions and infections in childhood (Bartley, 2004). It is also the

case that women living in low income households are themselves more likely to have been poorly nourished during their childhood and then to be poorly nourished during pregnancy. Therefore, they are more likely to produce low birth weight or premature babies. These children, growing up in low income households, are in turn more likely to be disadvantaged in terms of diet, overcrowding, safe areas in which to play and opportunities for educational achievement (Spencer, 2003). For example, an adolescent from a low income household is more likely to leave education at a minimum school leaving age, with few qualifications and to experience unemployment before entering a low paid, insecure and hazardous occupation, with for instance, no sick pay, poor holiday entitlements and no occupational pension scheme. The effect of income inequality on health reflects a combination of negative exposure and lack of resources held by individuals. In adulthood, those with limited financial resources are more likely to be exposed to health related risks (Graham, 2009). Compared with those in professional and managerial occupations, those in routine and manual occupations have lower earnings and poorer working conditions (Goldthorpe and McKnight, 2006). Such groups are also at greater risk of unemployment and particularly reoccurring unemployment, a situation well known for its detrimental effect on health (Bartley and Owen, 1996). Thus, the lifecourse approach attempts to explain how early life set individuals on a social pathway that impacts on their future circumstances and future health (Graham, 2009).

In relation to disabled people, nearly half of those people classed as disabled under the Disability Discrimination Act (2005), have no or low

qualifications, twice the proportion of non- disabled people (Centre for the Analysis of Social Exclusion, 2010).The rates of pay for disabled people are less than half than those who are not disabled and their average hourly earnings are twenty percent lower for men and women (Centre for the Analysis of Social Exclusion, 2010). The impact of socio-economic disadvantage, in terms of unemployment and reduced income that children and adults with learning disabilities are exposed to will be discussed further on in the chapter.

Psychosocial explanation

The psychosocial explanation is related to psychosocial factors that exist between the social and psychological, such as an individual's control at work (Shaw et al, 2007). This explanation focuses on how feelings arise within individuals, because of inequality, which then have a direct affect on biological processes (Bartley, 2004). Psychosocial explanations therefore, move away from the effects of material circumstances on health, to examine how health is related to people's perceptions of inequality (Marmot and Wilkinson, 2001). Thus, it cannot be singularly explained by the health damaging effects of impoverished conditions and those associated with absolute poverty (Marmot and Wilkinson, 2001).The psycho-social approach claims that the psycho social pathways associated with relative disadvantage act in addition to material disadvantage. Psycho-social responses, such as control, anxiety, insecurity and depression have negative effects on the health of individuals and are produced by the stress

of perceived unfairness related to subordinate positions in the social hierarchy (Wilkinson, 1996; Wilkinson and Pickett, 2009). This explanation therefore, relates to the negative effects associated with an individual's subjective experience of relative disadvantage and how this impacts on their health (Williams et al, 2009).

A number of studies have found that population health is less related to how wealthy a society is and more to how equally or unequally wealth is distributed. Life expectancy has been shown to be greater and is increasing not in the richest countries, but within those with smaller gaps between rich and poor. For example, the USA has twice the GDP per head than Greece, yet life expectancy is higher in Greece (Wilkinson, 1997). Life expectancy is also higher in countries such as Sweden, where there are more equal fiscal, economic and welfare policies and where their tax and welfare system mitigates poverty across all socio economic groups (Wilkinson, 1997).

Although difficult to measure and define, poverty is viewed as an unacceptable state for any society (Ridge and Wright, 2008).The United Nations (1995) has defined absolute poverty as a condition characterised by severe deprivation of human needs, such as food, safe drinking water, sanitation facilities, shelter, education and information. The concept of relative poverty has been explained by Townsend (1979:31):

Individuals, families and groups in the population can be said to be in

poverty when they lack the resources to obtain the types of diet,

participate in activities and have the living conditions and amenities

which are customary ... in the societies to which they belong.

Within this explanation, Marmot and Wilkinson (2001) argue that the negative emotions associated with relative poverty, are translated inside the body (neuro-endocrine pathways) into poorer health through the body's internal stress system:

When looking at the nature of the pathways which are most likely to link

physical disease to inequality, there is good reason for thinking that

psycho-social pathways are more important. Simply the fact that we are

dealing with the effect of relative differentness, rather than absolute

material standpoints points strongly in that direction

(Marmot and Wilkinson, 2001: 1234).

Furthermore, such inequality discourages trust and reduces cohesion within societies (Wilkinson, 1996). Thus, countries such as Britain have experienced the damaging effects of an increasingly unequal society. This is demonstrated by more people experiencing relative deprivation, thereby exacerbating existing social divisions and making it difficult to maintain communal bonds favourable to good health (Williams et al, 2009).

In contrast to the psycho-social explanation, Davey-Smith et al (1999) argue attempts to account for socio-economic differences in health, may be more usefully understood as a composite of socially constructed susceptibility and biological causation. Davey-Smith et al (1999), when examining the socio-economic distribution of particular cancers, argue such diseases present in a wide range of groups from different socio-economic circumstances, weakens the support for a theory of socially constructed susceptibility as sole cause. The social processes which concentrate exposure to such diseases as coronary heart disease, stroke, lung cancer and respiratory disease, increase the risk of these diseases in disadvantaged groups, and therefore bring about the inequalities in health (Ridge and Wright, 2008). For example, studies have shown that stomach cancer and stroke risk are associated with parental socio-economic position and therefore linked more closely to a person's circumstances in childhood, than to their social position in adulthood (Davey-Smith et al, 1999; Galobardes et al, 2008). Adverse socio economic circumstances in childhood increase the likely acquisition of infection with the bacteria helicobacter pylori, an infection implicated in stomach cancer. Declining rates of helicobacter pylori over the century have accompanied improving social conditions and can explain the falling death rates of stomach cancer (Davey-Smith et al, 1996). Shaw et al (1999) have argued that infections acquired during childhood may also be important factors in the production of the risks of stroke in adulthood.

Given the complexities of this topic, Bartley (2004) contests that no one approach can fully explain the complexity of how advantage and

disadvantage affect health overtime. Moreover, the evidence so far has not taken account of the position of people with learning disabilities. The next section reviews evidence that associates relative poverty with learning disability and its potential impact on the health of men with learning disabilities.

Socio-economic position and learning disability

A significant amount of work exists in relation to socio-economic position and the general population. However, there is very little evidence regarding social economic circumstances and the impact on the health of men with learning disabilities. Although the evidence suggests that families who support people with learning disabilities are found across the social hierarchy, families supporting a person with learning disabilities are significantly more likely to be located in lower socio-economic positions and experience poverty (Chapman et al, 2008; Emerson et al, 2009). People with learning disabilities are therefore more likely to be exposed to the social conditions associated with poorer health (Graham, 2005). Figures for Britain suggest that forty four per cent of children aged between five and fifteen with learning disabilities are living in poverty (Emerson, 2003). It is also the case that children who are born into poorer circumstances, are at greater risk of the forms of developmental delay associated with learning disability (Graham, 2005).

Although the evidence on socio-economic position and learning disability is

in its infancy, it is beginning to explain why people with learning disabilities are more likely to be in a reduced socio-economic position. When comparing over 12,000 children and young people with learning disabilities with children without learning disabilities, children with learning disabilities were more likely to be disadvantaged on all indicators of socio-economic position (Emerson and Hatton, 2005:42). This survey showed that thirty eight per cent of households with a child with learning disabilities experiencing income poverty, compared with thirty two per cent for those households without a child with learning disabilities. It also highlighted households with a child with learning disabilities considered to be in 'hardship', amounted to thirty six per cent, compared to twenty four per cent of a household without a child with learning disabilities. Nearly half, forty five per cent of the households with a child with learning disabilities were living in social housing, compared to twenty three per cent of a household without a child with learning disabilities. The survey by Emerson and Hatton (2005) showed thirty six per cent of households with a child with learning disabilities were without employment, compared to nineteen per cent without a child with learning disabilities.

To date, in the UK the majority of research regarding the socio-economic position and learning disability has been undertaken by Eric Emerson and Chris Hatton (Emerson, 2004; Emerson and Hatton, 2005; Emerson and Hatton, 2007 and Emerson and Hatton, 2008a; 2008b).

This body of work makes two key observations. First, the prevalence of learning disability is strongly related to socio-economic position across a diverse range of countries using different methods of assessment and different sampling approaches (Emerson and Hatton, 2009). Second, the strength of the association between socio- economic position and adults with learning disability varies significantly, by type and severity of disability (Chapman et al, 2008). Stronger associations are found as the severity of the learning disability decreases, therefore, people with mild learning disabilities are more likely to live in deprived neighbourhoods and be exposed to poverty and hardship (DH, 2001; Emerson, 2005). The stronger association with mild learning disabilities may seem counterintuitive, but people with severe learning disabilities are more likely to live with parent/carers, or in residential care.

However, although socio-economic gradients in the prevalence of learning disability are well documented, less is known about the causal processes that may account for these gradients (Emerson and Hatton, 2009). On the one hand, the evidence points to the possibility of the additional costs associated with raising a child with learning disabilities, which can lead to lower socio-economic position (Inclusion International, 2006). Other explanations have focused on lower parental cognitive ability, which can contribute to the risk of childhood learning disability and consequently the risk of lower socio-economic position (Spinath et al, 2004). In contrast, other research suggests that growing up in poverty is associated with increased exposure to a wide range of material and psychosocial hazards, which can

impair cognitive and intellectual development (Bradshaw and Finch, 2003; Emerson and Hatton, 2009). This include preterm, low birth weight, fetal growth restriction, exposure to toxins and teratogens (an agent that interrupts or alters the normal development of the foetus, such as chemical radiation), poorer nutrition, including reduced rates of breast feeding, poorer housing conditions, poorer educational opportunities, injury and accidents and exposure to more hazardous neighbourhoods (Bradshaw and Finch, 2003; Marmot and Wilkinson, 2006).

Impact of reduced socio-economic position on people with learning disabilities

There is less evidence explaining how the poorer socio-economic position impacts on adults with learning disabilities. However, in adulthood, in developed countries, across the spectrum of learning disability, it is acknowledged this group of people experience higher rates of unemployment and greater exposure to poverty (Fujiura, 2003).

More recently, detailed surveys and reports (Emerson and Hatton, 2007; Emerson and Hatton, 2008a) have begun to provide clarity on the socio-economic positions associated with people with learning disabilities. Specific examples of socio- economic disadvantage and learning disability have been highlighted in a report by Emerson and Hatton (2008a), which adopted indicators from the Millennium Poverty and Social Exclusion Survey (Gordon et al, 2005). In addition to the type of accommodation associated with

people with learning disabilities, a range of different social circumstances affecting this group of people were surveyed. In the survey by Emerson and Hatton (2008a), specific examples of material hardship were reported by people with learning disabilities. Of the 1500 people covered in the survey, over a third of people with mild to moderate learning disabilities reported not being able to afford two or more items in a list that included new shoes, going out, new clothes, or taking a holiday. In terms of where people lived, those people with mild learning disabilities who lived in private accommodation were living in areas characterised by high levels of social deprivation (Emerson and Hatton, 2008a).

The evidence suggests that having a learning disability is likely to increase the risk of exclusion from the workforce, increase the risk of long term unemployment and consequently result in social disadvantage (Emerson, 2005). One study found that only seventeen percent of people with learning disabilities are in employment, compared to sixty seven percent of men and fifty three percent of women of working age without learning disabilities in the England (Emerson et al, 2005). Low income and unemployment are key factors highlighted in a recent report that examined poverty and people with learning disabilities in the UK (Emerson and Hatton, 2008a). In short, employment is still not an integral feature of the lives of people with learning disabilities (Maguire, 2009) and people with learning disabilities are more likely to be reliant on income support.

The 'Working Lives' study, which investigated the role of day centres in supporting people with learning disabilities into employment (Beyer et al, 2004), found that most people with learning disabilities want to work, even if they were not working at that time of being interviewed and that they would like paid work. There have been a number of political initiatives which have attempted to promote work opportunities for this group of people. The '*Valuing People'* strategy Department of Health (2001), for example, made clear its intention:

enable more people with learning disabilities to participate in all forms of employment wherever possible in paid work, and to make a valued contribution to the world of work

(DH, 2001:8).

The strategy outlined its aim to bring in a variety of new initiatives to remove some of the difficulties employment presents people with learning disabilities. For example, 'Work-Step' programmes aimed at providing individually tailored packages of support for people with disabilities, plus Job Brokers and New Deal for Disabled People, which aim to make better links between Department of Health and Department for Education and Employment. In 2003, the Department for Work and Pensions published its proposals for new '*Pathways to Work'*. This was followed in 2005 by '*Improving the Life Chances of Disabled People'*, which stated that by 2025 disabled people in Britain would be respected and included as equal

members of society, with equal job opportunities being a key feature of this (Prime Ministers Strategy Unit, 2005:3). Although these reports reflect attempts to improve the employment situation for disabled people, the Department of Work and Pensions (2006) acknowledged more progress was needed to allow people with disabilities to benefit more from the introduction of these specific welfare reforms. The message to promote more equal work opportunities for people with learning disabilities was reiterated in the more recent document *Valuing Employment Now* (Department of Health, 2009). This document set out new goals to increase the numbers of people with learning disabilities into employment by 2025. It intends to raise expectations across the health and social care system emphasising this population should have the opportunity to work (Department of Health, 2009).

Impact of socio-economic disadvantage on the health of people with learning disabilities

Davey Smith et al (1996) report how a cluster of neo-material conditions affects the health of the general population has not been extended to the learning disability population specifically. In the same way, the substantial evidence that socio-economic disadvantage is associated with poorer chances of both physical and mental health (Marmot, 2010), is not inclusive of people with learning disabilities.

The following studies reveal the association between socio-economic

position and potential health problems, referring to both children and adults

with learning disabilities. According to Emerson (2004) and Graham (2005),

socio-economic disadvantage is an important factor in the negative life

events and high rates of emotional, behavioural and health difficulties

experienced by people with learning disabilities. A few studies have begun

to explore self reported health and well being indicators and socio-economic

position in relation to people with learning disabilities (Emerson and Hatton,

2008a) and the contribution of socio-economic position on the health of

children and adolescents with learning disabilities (Emerson and Hatton,

2008b).

Emerson and Hatton (2008b) have attempted to estimate the extent to

which the increased risk of poor physical and mental health among children

and adolescents with learning disabilities may be associated with their more

socially disadvantaged position. Examining survey data regarding 10,438

British children, Emerson and Hatton (2008b) adopted household income,

occupational prestige and maternal education as the main indicators of

socio-economic position. The main finding was that amongst the different

groups, (those with emotional, and those with behavioural and conduct

disorders) the differences in socio-economic position accounted for twenty

four per cent increased risk of poor health, a twenty three per cent increased

risk of behavioural disorders and a thirty seven per cent increased risk of

emotional disorders. Emerson and Hatton (2008b) argue that socio-

economic disadvantage may account for a significant proportion of

increased risk of poorer health and mental health of children and adolescents with learning disabilities. Furthermore, in a survey of men and women with mild and moderate learning disabilities, Emerson and Hatton, (2007) report that material and social hardship was more strongly associated with a variation in health status, than either employment status, or the social deprivation associated with where individuals lived. In the same study, it was stated that little is known about whether the processes that mediate social economic disadvantage for people with learning disabilities are similar or dissimilar to the general population (Emerson and Hatton, 2007).

As previously highlighted, other factors reported as being associated with socio-economic position and having a direct impact on health, are an individual's social network, friendships and social participation in their communities (Wilkinson 1996). This explanation has not been extended to include people with learning disabilities. However, Emerson et al (2009) suggests in societies with high levels of inequality, people with learning disabilities are likely to be seen (and see themselves) at the lower end of the status hierarchy, with the associated negative effects on their health (Wilkinson and Pickett, 2009). Emerson and Hatton (2008a) reported in their survey that people with learning disabilities were less likely to have contact with friends and members of their family if they were not living with them. The seminal work by Edgerton (1967) highlighted the difficulties faced by people with mild learning disabilities going into adulthood with very few forms of social support and/or social networks. This work is most noted for

its focus on social isolation and poor health experienced by people with learning disabilities, as they tried to cope with community life after being in a 'long- stay' hospital. Furthermore in England, over fifty per cent of people with learning disabilities live with their carers (DH, 2001); the opportunities to develop friendships outside of the family arrangement could be reduced, potentially leaving the individual socially isolated. There have been few studies examining how men with learning disabilities, living with carers, or independently, perceive and experience friendship and its impact on health.

In another study, Seltzer et al (2005) compared people with mild learning disabilities living on their own with those without learning disabilities across a number of areas, including social participation; physical health and psychological well being. The most significant difference was in the area of psychological well being, where people with mild learning disabilities reported higher levels of stress and depressive symptoms, a lower sense of purpose in life and fewer opportunities for personal development (Seltzer et al, 2005). Moreover a study by Hardy (2002), which explored the perspectives of people with learning disabilities, in relation to what they considered affected their mental well being and causes of stress, found the main factor affecting individual mental health was not having friends and meaningful relationships.

As highlighted earlier, there have been declining rates of helicobacter pylori in the non disabled population (Davey- Smith et al, 1998). However, there is

still a higher occurrence of helicobacter pylori linked to stomach cancer in adults with learning disabilities (Hogg and Tuffrey-Wijne, 2008). This highlights they potentially retain exposure to such disorders resulting from the effects of their impairment and their reduced socio-economic position.

Increased rates of smoking amongst those in more socially disadvantaged areas, has been reported as an important outcome of how people respond to the psychological impact related to their social circumstances (Graham and McDermott, 2005). Although the evidence is limited regarding the prevalence of smoking amongst people with learning disabilities, the available evidence reports lower smoking rates amongst this group of people compared with the general population (Whitaker and Hughes, 2005). Within the learning disability population itself however, there is some evidence to suggest that smoking is associated with those with more mild learning disabilities (Robertson et al, 2000) and amongst men (Rimmer et al, 2000). Only Graham (2005) has highlighted the necessity for future research to begin to understand how the health of people with learning disabilities is compromised by social disadvantage.

Furthermore, there have been no specific studies identified that qualitatively explore any association between people with learning disabilities' socio-economic position and their health, from their own perspective. Little is known from men with learning disabilities regarding whether their type of living accommodation, for example with carers, or living independently,

affects their socio-economic status and the potential impact on their health. Despite a thorough literature review, no literature has been identified that explores the perspectives of men with learning disabilities regarding the processes involved in living through the impact of relative poverty.

Conclusion

This chapter has reviewed the evidence associated with the impact of relative poverty on the health of men with learning disabilities. The chapter has shown that inequalities in health continue to exist across socioeconomic groups (Marmot, 2010). These differences follow a social gradient, the higher up the social hierarchy the lower the risk of ill health and premature death (Marmot, 2010). The chapter then reviewed the three main types of explanation which have been put forward to account for current patterns of health inequalities (Shaw et al, 2007; Graham, 2009; Lynch et al, 2000; Wilkinson, 1996; Marmot and Wilkinson, 2001; Davey-Smith et 1999; Williams et al, 2009). However, given the complexity of how society can impact on health, no one explanation can fully account for current patterns of health (Bartley, 2004). The chapter suggests it is the impact of more disadvantaged circumstances; whether material or psychosocial and the impact on behaviour that best account for current patterns of health.

Subsequent parts of this chapter have demonstrated that people with learning disabilities are likely to live in conditions associated with socio-economic disadvantage (Chapman et al, 2008). It is therefore logical to

suggest that this group of people are more likely to experience poorer

chances of psychological and physical health, resulting from such

conditions. The possibility of this has begun to be mapped out through a

number of studies. These have identified how people with learning

disabilities are more likely to be unemployed, have lower pay and have

poorer mental health. They are also more likely to be socially isolated which

they themselves have identified as significant for their mental health.

Despite these findings, a thorough literature review could not identify any

evidence of people with learning disabilities' own perspective on the

association between their economically disadvantaged position, their

physical health and the processes involved. This thesis aims to address this

issue by exploring how men with learning disabilities' experience and

perceive the effects of relative poverty on their health.

Chapter 4

The significance of gender for the health of

men with learning disabilities

Introduction

This chapter discusses how gender is a further critical dimension to how men with learning disabilities experience and perceive health. The chapter will begin by highlighting the key evidence relating to patterns of men's health in the UK. It then explores explanations for these patterns and particularly how social scientists have begun to focus on the gendered nature of men's health. In so doing, it highlights the contemporary shift to the notion of multiple masculinities and draws on Connell's (1995) concept of *hegemonic masculinity* to help promote greater understanding of current patterns of men's health. The chapter goes on to review previous research undertaken with disabled men regarding masculinity and health and then discusses the few studies that have considered the notion of masculinity, in relation to men with learning disabilities. The chapter concludes by suggesting that previous research in this area is limited and that studies have not explored the ways in which men with learning disabilities perceive and experience their gender and the ways in which this can impact on their health.

Gendered patterns of men's health

Whilst men and women's health has continued to improve

(www.statistics.gov.uk, 2010), men's health has increasingly become a

public health concern primarily because of men's shorter life expectancy

(Robertson, 2007). The average life expectancy for men in the UK is

currently four years less than for women; a newborn baby boy can expect to

live to 77.4 years and a newborn baby girl to 81.6 years (ONS, 2008). This

difference in life expectancy is apparent across all age groups, with the most

notable difference of 5.3 years occurring between the ages of 35 and 55

(ONS, 2005). However, whilst women live longer than men, the gender gap

in life expectancy has narrowed in recent years falling from 6 years in 2006

to 4.2 years in 2007 (ONS, 2008). Studies which have sought to account for

the recent reduction in differences in life expectancy between men and

women, have attributed it to the rise in numbers of women in the workplace

and the reduction in gender differences in relation to smoking (Amos and

Bostock, 2007). In addition, there is evidence of increasing prevalence of

heavy drinking among women, which leaves them vulnerable to illnesses

traditionally experienced by men (Brettingham, 2005). That said, however,

men are seventy percent more likely to get cancers that affect both men and

women and are more likely to die before the age of 65 from the most

common cancers affecting both sexes (Men's Health Forum, 2010). In

addition, men are far more likely to die prematurely from Coronary Heart

Disease (CHD), which is second to cancer as the leading cause of death for

both men and women (DH, 2008b).

Explaining patterns of men's health

It is generally acknowledged that biological factors may contribute to the

different patterns of health experienced by men and women. Men's tendency to accumulate fat around the waist, for example, is a risk factor for other diseases and contributes to metabolic syndrome (DH, 2008b). Metabolic Syndrome is a cluster of risk factors, such as high blood pressure, insulin resistance and cholesterol abnormalities, which are associated with an increased risk of cardiovascular disease, stroke and Type Two diabetes. In contrast, women are more likely to experience higher incidence of chronic diseases (Payne, 2006). For example, women are four times more likely than men to experience Fibromyalgia, which is the second leading arthritic disease after osteoarthritis. Women are also at risk of increased incidences of gender specific conditions after the menopause, such as osteoporosis and increased risk of heart disease (Payne, 2006).

When seeking to explain why men's health is patterned differently to women's, commentators have often pointed to differences in damaging health-related behaviours; i.e. activities adopted with negative consequences for health, which are more common among men (DH, 2008b). Smoking is a concrete example of the kind of health damaging behaviour more likely to be adopted by men. Traditionally, more men than women smoked and although the proportion of men and women who smoke is now similar, men continue to smoke more heavily and to smoke 'high tar' cigarettes (Payne, 2006). Men are also more likely to be overweight and obese than women (ONS, 2006). Men's propensity to put weight on during the middle years of life carries increased risk of certain disorders, such as hypertension, and some forms of cancer, such as colon and prostate cancer

(WHO, 2002). Men are also more likely than women to drink above

recommended amounts of alcohol, to binge drink and to take illicit drugs

(ONS, 2006). Although recent reports have suggested a levelling out of

alcohol related deaths between men and women (ONS, 2005), in 2008 two

thirds of alcohol related deaths were male (ONS, 2010). Men also appear

less likely to consult health services than women (Payne, 2006). Women are

higher consulters of health care for every age group compared to men, with

the widest difference of twenty-nine percent taking place in mid-life (DH,

2008b). Studies have shown that men also appear less willing to use mental

health services, have less positive attitudes towards health service use and

are less likely than women to decide in favour of consultation, in either

primary care or specialist services (Mackenzie et al, 2006).

Not surprisingly, therefore, men are often viewed as responsible for their

poorer health outcomes (DH, 2008b).The *Gender and Access to Health*

report (DH, 2008b) provided evidence regarding differences between men

and women's health and reiterated the need for men to stop engaging in

certain health damaging behaviours. However, focusing on men's health-

related behaviours to explain current disparities in the health of men and

women, fails to provide explanations for why many men behave as they do

and their understandings in relation to their health (Courtenay, 2011).

Sociology of masculinity

A deeper level of explanation has been pursued by social scientists, who

argue that the ways men demonstrate masculinity, may encourage them to adopt certain health damaging behaviours, such as excessive smoking, alcohol consumption and dangerous sports (Doyal, 2000; Courtenay, 2011). Strongly endorsed masculine ideals which portray men as stoic, robust and strong of mind, may also impact on men's health related behaviour as well as their decisions as to whether they access health care services (Courtenay, 2011). Social scientists, therefore, have sought to explain men's health related behaviour in terms of how men construct gendered identities. These activities can be seen as a form of currency in transactions between groups of men and between men and women, which are continually 'played out' in the demonstration of gender:

The doing of health is the doing of gender...health actions are social acts and can be seen as a form of practice which constructs the person in the same way that both social and cultural activities do

(Saltonstall,1993:12).

Thus, investigations underpinning these types of explanations have often sort to understand the processes by which men are socialised into adopting masculine identities. Sex role theory, for example, was one of the first sociological explanations to gain widespread currency as a means of understanding how men behave (Pleck, 1994). The basic assumption in sex role theory is that social expectations about men and women's status in society produce conformity to a given role and related sets of functions

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(Robertson, 2007). In terms of men, this includes being the 'hunter gatherer' (breadwinner), being territorial, being a father and demonstrating sexual promiscuity, all of which are seen as expressions of manhood that have evolved to ensure the survival of the species. Difficulties can arise when individuals cannot fulfil particular social roles. Thus, while society may expect one of men's roles to be the main economic provider for the family, failure to achieve this role can result in what Pleck (1994) refers to as *male gender role strain.* Moreover, the greater the internalisation of such cultural norms of masculinity for an individual, the greater the role strain when these norms cannot be lived up to (Pleck, 1994). In addition, long working hours, pressure to succeed, risk taking and the stress related to enacting these can create psychological and physical ill health (Robertson, 2007).

Whilst it initially gained in popularity, a number of criticisms have subsequently been levelled at sex role theory as an explanation for the way in which men are socialised into their gendered roles. Fundamentally, the ideas about masculinity propagated by this perspective can be referred to as 'essentialist', in that it does not account for the possibility of change, but present a rigid/fixed view regarding gender (Coles, 2009). It also presents men as a homogenous group and as such fails to address differences in power relations between different groups of men (Segal, 1997). In contrast, more recent work from within the field of men and masculinities has sought to explore a more variable range of masculinities, which shifts away from such fixed or essentialist views of gender.

Hegemonic masculinity

The men and masculinities literature conceptualises masculinity as plural, with 'masculinities' being influenced by wider socio-cultural factors and determined by identity and broad social structures (Coles, 2009). One significant aspect of this shift has been Connell's (1995) concept of hegemonic masculinity, which has been highly influential in analysing men's lives and has been used by commentators working in the field of men's health (e.g. Noone and Stephens, 2008; Dolan, 2011). Connell (1995: 81) identifies a range of masculinities; hegemonic, subordinated and marginalised, defined in terms of associated practices. In short, certain forms of masculine practice gain dominance at the expense of other configurations, which become subordinated to and/or marginalised from the dominant hegemonic ideal.

Connell (1995) defines hegemonic masculinity as the dominant way of performing maleness, which men seek to align themselves with. Men, therefore, aim to emulate dominant forms that are linked to being capable, successful and in control. Alongside men's endorsement of hegemonic ideals is their rejection of feminine ideals (Coles, 2009). This contributes to the construction of hegemonic masculinity and the oppression of women and less powerful men. However, whilst hegemonic masculinity has become the idealised/dominant form of masculinity, it is not the most practised, primarily because most men cannot live up to its ideals. Connell's (1995) framework, therefore, also recognises the hierarchical and multifaceted

nature of masculinity through the discussion of subordinated and marginalised masculinities. One illustration of this is the way working class men may construct masculinity, through the demonstration of physical strength. In these situations, where working class men are denied the resources and social status to fulfil hegemonic ideals, they construct their gender identity in ways that validate them as men, despite being within subordinated/ marginalised positions (Dolan, 2011).

Thus, hegemonic masculinity relates to cultural dominance in society as a whole, and it is within this overall framework that there are specific gender relations of dominance, between men and women, but also between different groups of men (Connell, 1995). In short, therefore, hegemonic masculinity represents patriarchal dominance over females, but also opens up the notion of men's dominance over other men (Connell and Messerschmidt, 2005). However, the concept is not seen as leading to regimented behaviour across the whole male population. It is defined as a fluid concept, seeing different men as benefitting in different ways from the 'patriarchal dividend'; i.e. all men benefit from patriarchal power over women, but not all men benefit to the same extent (Connell, 1995). Moreover, whilst hegemonic masculinity is dominant, it is not uniformly adhered to, as it refers to how particular groups of men adopt positions of power and status and how they justify and reproduce practices that promote their dominance. In furthering our understanding of masculinity, the concept of hegemonic masculinity presents 'a more holistic understanding of gender hierarchy' (Connell and Messerschmidt, 2005: 848). In short, according to

this theoretical perspective, all men will recognise core aspects of what it means to be male, but how they achieve it will vary dependent on their circumstances.

Although hegemonic masculinity has been extensively used as a research framework within studies of men's health, it is a contested concept and its usefulness for exploring masculine identities has received criticism. Coles (2009), for example, argues that hegemonic masculinity is frequently discussed at a structural level, with limited consideration given to the strategies men use to negotiate masculinities in their everyday lives. This argument could reduce men's behaviour to a negative set of stereotypical practices (aggression and violence), that do not reflect multiple forms of masculinity (MacDonald et al, 2005), or promote positive male behaviour, such as being a supportive, helpful partner or husband.

In light of this, it has been argued that in order to fully understand the influence of social context on men's identities, hegemonic masculinity should be viewed as multi-faceted and context dependent (Coles, 2009). In this way the dominance of hegemonic masculinity is susceptible to the challenges of subordinated and marginalised masculinities, such as gay men being good at sports. Commentators (e.g. Coles, 2009) have therefore started to refer to a *multiplicity of masculinities* that are displayed in various ways, by different men, or by the same men at different times. For example, the working class man may be subordinate to the middle class business

man in the labour market, but the working class man who demonstrates the ability to excel at a particular hobby, may be viewed as having authority amongst his working class peers (Coles, 2009).

Men, masculinities and health

There is a growing body of work that examines the role of masculinities in men's health, which seek to widen our understanding of men's perception and experience of health. Noone and Stephens (2008), for example, have explored how hegemonic masculinity influenced how men made sense of their help seeking behaviour when they had concerns about their health. This study demonstrated how men made use of primary healthcare but sort to distance themselves from notions of 'hypochondria', which was associated with women/femininity, by defining themselves as 'legitimate' users of health services. In doing so, they also presented themselves as knowledgeable about health issues and could not, therefore, be accused of attending for trivial reasons, or of impeding on the time of medical practitioners. Thus, while they did not adopt behaviour associated with hegemonic masculinity, i.e. they sought health advice by presenting their behaviour in terms of genuine medical conditions, they sought to legitimise their behaviour and continued to mark themselves as 'proper' men (Noone and Stephens, 2008).

In another study regarding fire-fighters, O'Brien et al (2005) highlight how in certain social contexts, demonstrations of hegemonic masculinity can be in

opposition to what might generally be expected as dominant male behaviour in relation to their health. They found that while these men generally reinforced certain masculine ideals (based on their ability to endure illness), not all of the participants presented as reluctant help seekers. As a group, these fire-fighters highlighted the importance of promptly seeking medical help as illness might affect their ability to do their work. Thus, in the context of a highly masculine occupation, masculine identities were based on having a strong healthy body, rather than on negative health behaviours, or a reluctance to seek medical help. In both the O'Brien et al (2005) and the Noone and Stephens (2008) studies, men define health seeking behaviour in terms of maintaining their status as men. These studies also demonstrate how demonstrations of masculinity can be context dependent. O'Brien et al (2005), for example, showed that the men were keen to seek out medical help when it concerned their job as fire-fighters. Similarly, Noone and Stephens (2008) demonstrated how men legitimised their access to health services to help validate their masculinity.

A study by Emslie et al (2006), which explored the views and experiences of men with depression, found that the pressures associated with hegemonic ideals could be heightened when men experienced mental health problems and even push men towards contemplating suicide. However, it was also the case that some men were also able to construct a narrative which reflected other ways of being male, which often challenged traditional hegemonic enactments (Emslie et al, 2006). For example, this group of men emphasised their creativity, sensitivity and intelligence, redefining their

difference (to hegemonic ideals), as a positive feature, albeit often with certain caveats, not being like women, which drew upon more recognisable aspects of hegemonic masculine identity.

In another study, Oliffe (2005) examined men's experience of impotence following treatment for prostate cancer. An appreciation of men's variable approaches to negotiating masculine identities provided a useful theoretical background to the topic under review. Following a prostatectomy, some men experienced unexpected physical changes as well as changes in their libido and erectile function. Oliffe (2005) shows how men dealt with their impotence following prostatectomy in different ways. Some participants dismissed impotence and decided that surviving and opting for cancer treatment was more important than their potency. Other men redefined masculinity by reviewing their relationships with female partners, with more of a focus on intimacy than sexual penetration. This led the participants to construct their masculine identities in direct consultation with female partners, reiterating how masculinity is also constructed in relation to femininity as well as other masculinities. Taken together, this growing body of research indicates how the shift to the notion of masculinities and the concept of hegemonic masculinity, has widened our understanding regarding patterns of men's health. However, whilst acknowledging this, these concepts have not been extended to the experience and perceptions of men with learning disabilities and their health.

Disabled men and the construction of masculinity

Whilst the shift towards masculinities and the concept of hegemonic masculinity has emerged as useful when analysing men's health, there is little evidence about how men with a range of disabilities construct masculinity and its impact on their health. There has been some research conducted with men coping with chronic illness and impairments. Charmaz (1994), for example, explored how the identity of men with chronic illnesses was affected by assumptions about their masculinity and identity. The traditional assumptions about male identity being active, stoic and brave created some tensions. On the one hand, these assumptions encouraged men to take risks, to enable them to deal with the uncertainty of illnesses and respond positively when recovering from major illnesses. On the other hand, attempts to live up to traditional masculine ideals also fostered a rigid stance and set of responses within the men, that were more likely to lead to depression.

More recently, Gibson et al (2007) explored the identities and social position of men with muscular dystrophy. This study examined how these men responded to dominant debates regarding disability, masculinity and medical technologies. These men's accounts revealed that they were materially, socially and symbolically marginalised. This was illustrated through the inaccessibility of buildings, through social arrangements that restricted their abilities to engage in community life and the different ways their visible differences were negatively perceived in social situations. In

another study, Burns et al (2009) talked to young men who were disabled through spinal cord injuries. This study sought to explore how these young men integrated the injury into their sense of masculine masculinity, as well as how the disability interacted with other aspects of their masculine identity. Burns and colleagues found the negative associations between the disability and the dependency associated with their condition, challenged their masculine identities, affecting their ability to integrate their injuries positively into their identity. However, research on masculinities and the health of disabled men has not, to date, included men with learning disabilities.

Masculinity and the health of men with learning disabilities

A specific focus on masculinity and the health of men with learning disabilities is not apparent in the literature and no work exists that takes account of the recent shift towards the notion of masculinities in relation to this group of men. Research by Wilson (2005; 2009) has demonstrated how the concept of masculinity was constructed by care staff in different care settings for men and boys with moderate and profound learning disabilities. This work refers to the term 'conditionally masculine', drawing on how female care staff controlled or 'conditioned' the extent of masculinity for individuals with profound disabilities. For example, the care staff felt the greater the disability the more they had to encourage masculinity by dressing and grooming the men in a way that they felt looked 'manly'. Wilson (2009) argues that these individuals have reduced autonomy and communication, resulting from their impaired cognition and the female care

staff acted as 'masculine surrogates'. In contrast, the boys and men with

moderate learning disabilities in the study were able to refer to symbols of

maleness, such as firemen and using 'masculine' language, such as

swearing, and therefore the care staff were less inclined to limit or condition

their masculinity. These studies also highlight how masculinity is a

changeable construct (Adams and Savran, 2002). Thus 'conditional

masculinity' in the context of Wilson's work, highlights the limitations of

disability to express maleness, but not being male. This work highlights the

potential for men with mild learning disabilities to grasp the concept of

masculinity, but does not go as far as exploring how the men understand

masculinity and its association with their health. Wilson (2009) highlights the

importance of the brain and cognitive ability as they relate to construction of

disabled masculinities, foregrounding the opportunity for men with learning

disabilities to be able to construct and understand masculinities.

In a recent thematic review of learning disability research articles that

focused on male and female health, Wilson et al (2010) found much less

research on male health compared with female health. The literature

regarding men focused on topic areas such as the problematic sexual

behaviour of men with learning disabilities, health and well being (population

studies related to different presentations of specific conditions associated

with genetic disorders) and studies related to the language development of

boy's with specific conditions. Unlike conventional literature reviews that

focus on research findings and methodological issues, this review was

concerned with identifying the aforementioned topic areas that researchers

had examined, in relation to gender specific studies involving people with learning disabilities. This review also reported that the existing articles referred to male health as 'problematical' or male sexual health behaviour as abusive, compared with the articles concerned with women with learning disabilities that focused more on health promoting strategies.

Some work has been undertaken that refers to the health damaging behaviours associated with men with learning disabilities. Taggart et al (2006) identified that among people with learning disabilities who admitted to substance abuse (alcohol and smoking), nearly two thirds (61per cent) were male, with alcohol being the most misused substance. Other work has examined the service provision available to people with learning disabilities who have issues with alcohol abuse, or who take illicit drugs (McGlaughlin et al, 2007).

In another study, Booth and Booth (2002) examined the role men played in the lives of mothers with learning disabilities, both as parents and fathers themselves. Although the paper did not focus explicitly on a gendered analysis of male health, Booth and Booth's work (2002) contributes to understanding how men with learning disabilities construct the concept of masculinity. Their qualitative data highlighted how the men with mild learning disabilities were largely supportive partners and fathers. This picture differs from the dominant theme of problematic behaviour often associated with men with learning disabilities, who are often identified as

perpetrators of sexual abuse, as in the work of Wilson et al (2009) and which is reported elsewhere (Holland et al, 2002; Thomson and Brown 2010).

There has been some qualitative research drawing on the viewpoint of women with learning disabilities themselves, regarding their gendered experience of health and their perspectives on this. McCarthy (1998), for example, carried out interviews with women with learning disabilities regarding their experiences of sexuality and their bodies. This work addressed women's feelings about their body and appearance as well as related issues of power and control. This work showed that women with learning disabilities feel the pressure of social gender prescriptions regarding weight, body shape and norms of femininity (McCarthy, 1998). In a more recent study by McCarthy and McMahon (2008), twenty three women with learning disabilities were interviewed specifically on their current and past use and knowledge of contraception. This study showed that the women's knowledge of how contraception worked was limited and half of the women also lacked basic knowledge regarding reproduction (McCarthy and McMahon, 2008). McCarthy (2009) also highlighted that women with learning disabilities felt that other people made the key decisions for them in relation to when to start contraception and which method to use.

Thus, while the views of women have been sought on gender roles and

health, no similar work has been identified with men with learning disabilities. Some quantitative work has been undertaken that examines the views of care staff on the penile hygiene of men and boys with learning disabilities (Wilson et al, 2009). Work has also investigated the need for more awareness and advice around testicular cancer for men with learning disabilities, regarding mainstream health care practitioners (Peate and Maloret, 2007). However, despite an extensive literature search, no work could be identified that specifically explores the viewpoints of men with learning disabilities regarding how they understand masculinity and their health.

As previously stated, people with learning disabilities have a series of specific health conditions when compared to the general population (Lantman-de valk, and Walsh, 2008). However, there is limited research exploring men with learning disabilities' awareness of their impairment related health conditions and their willingness to seek out health advice. Whether men with learning disabilities respond to their marginalised position in the same way as other men has also not been explored. Moreover, how this group of men perceive and experience gender hierarchies and its potential impact on health, is unknown. No specific work has explored whether men with learning disabilities are more likely to adopt similar health damaging behaviours to non-disabled men. As Kerr (2002) has argued, it cannot be assumed that the way in which men in general adopt health damaging behaviours, apply equally to men with learning disabilities. This combined with the increased patterns of specific health conditions evident

within the learning disability population, compared with the general population (Emerson and Baines, 2010), potentially puts their health at further risk of deterioration.

Conclusion

This chapter has reviewed the significance of gender on the health of men with learning disabilities. The chapter has demonstrated how social scientists have sought to deepen our understanding of the differences between men and women's health by exploring the gendered nature of men's health (Courtenay, 2011). In doing so, the chapter showed how work has begun to acknowledge that masculinity is multi-faceted and context-dependent. Conceptualising masculinities rather than masculinity also recognises that structural hierarchies exist amongst the male population with implications for health (Coles, 2009). The chapter has also shown how the concept of hegemonic masculinity (Connell, 1995) has been employed to promote a more nuanced approach to the study of men's perspectives on and experience of health (O'Brien et al, 2005; Emslie et al, 2006). Thus, the chapter concludes that the notion of masculinities and the concept of hegemonic masculinity can provide a more incisive and nuanced explanation for the way men behave in relation to their health. However, to date, there is only limited evidence describing how disabled men construct masculinity and its impact on their health and no evidence could be found that takes a gendered approach to the health of men with learning disabilities. The chapter concludes that gender is another critical social

dimension that has the potential to reveal a deeper understanding of the everyday lives of this group of men. This thesis therefore intends to contribute to addressing this situation by exploring how men with learning disabilities perceive and experience their masculinity and its impact on their health.

Taking the key social divisions forward

This chapter, together with proceeding chapters on disability and relative poverty, has identified the significance of social divisions on the health of men with learning disabilities, which require further examination. In doing so, it has also highlighted the relative neglect of the perspectives and experience of this group. It has also indicated the interplay that can occur between these three separate social dimensions, which impact on the health of men with learning disabilities. For example, while experiencing the impact of disablilist healthcare and physical impairment associated with learning disability on their health, men with learning disabilities also face disabilist employment conditions and low income levels. These factors contribute to relative poverty with undermining effects on health. Meanwhile, in the absence of the men's own accounts, evidence is lacking on whether or not adherence to dominant notions of masculinity may undermine their use of healthcare, or be a factor in victimisation by others.

The interplay between these three social dimensions provides a crucial theoretical linkage and commonality for the thesis. Critical to furthering an

understanding of the health of men with learning disabilities therefore, is acknowledging the relevance of each social dimension and any potential interplay between each social dimension, namely disability, relative poverty and gender. This has been neglected within the literature to date.

The following chapters explore the outcomes of gaining the perspectives of men with learning disabilities regarding these potentially significant social dimensions and how they impact on their experience and perceptions of health. This begins with an account of the methodology and methods employed within the fieldwork.

Chapter Five

Methodology employed in the empirical study of the perspectives and experience of men with learning disabilities

Introduction

This chapter focuses on the methodology employed in the study. This sought to access the perspectives and experiences of men with learning disabilities regarding the impact of disability, relative poverty and gender on their health. It begins by discussing the key ontological and epistemological principles influencing the research design. These recognise individual agency, as well as the contextual conditions that shape individuals' perspectives and experiences. In light of this, the chapter then presents its rationale for a research methodology that privileges men with learning disabilities' accounts and explores their subjective and experiential understandings of disability, relative poverty and masculinity from within their own life context. It then moves on to elaborate on the methods that were employed to enable the accounts of the men to be drawn out. It will be argued that the reality for many people with learning disabilities remains one of exclusion. One means of challenging this through research, has been the development of work seeking to reveal their own perspectives on their own situation.

As with research with other vulnerable populations, enabling meaningful involvement and gaining informed consent present certain interpersonal and

specific challenges. The chapter demonstrates how I strived to develop a relationship with the participants that attempted to level out the balance of power, between the researcher and participant. This took account of cognitive difficulties, and providing the right setting for the men's commentaries to be heard. In doing so, the fieldwork was aligned to a participatory approach and this chapter demonstrates the value of this in building up the necessary relationship with the participants. Men with learning disabilities were involved in the research in two main ways, as members of the steering group and as participants, through semi-structured interviews. How this was carried out and the benefits of doing so in meeting the overall aims of the research will be reviewed and reflected on. The ethical considerations associated with conducting this research are reviewed, as well as the significance of my professional identity as a learning disability nurse, and role as researcher. Finally, following a discussion of the process of analysing the accounts that I undertook to illuminate the experiences and perspectives of the men, the potential limitations of the research will be considered.

Perspectives informing research design

Interpretive sociology

Traditionally, research studies related to the learning disabled population tended to focus on furthering medical and epidemiological understandings (Lennox et al, 2007; Melville, et al, 2007). However, many important facets of people's everyday lives linked to disability, socio-economic position and

gender are difficult to study by established medical and epidemiological methods (Sandberg, 2005). These methods can say little about subjective experiences and often complex and varied social relationships, which shape health and illness (Sandberg, 2005). In contrast to medical and epidemiological evidence, the interpretive perspective refers to a category of understanding that stakes a claim for the interpretation of everyday life by individuals and groups, and without which a social existence would be impossible (Swingewood, 2000). Interpretive sociological perspectives also recognise that sociological inquiry is not a neutral activity and has often been concerned with the lives of people labelled as outsiders or outcasts (Chappell, 2000). As such, the interpretive perspective has sought to sympathise with disabled people and articulate their experience of the world (Chappell, 2000). This endeavour has seen a growing body of disability research in general that aims to promote an understanding of the experience and daily lives of disabled people (Shakespeare, 2006; Ryan and Runswick- Cole, 2008; Vickerman and Blundell, 2010).

Disability research

It is against the background of challenging social disadvantage, that more inclusive research strategies, enabling the involvement of disabled people have been developed (Priestly et al, 2010). Knowledge generated in this way, has evolved from democratic ideas that have sought to prioritise people's independence, autonomy, and inclusion, with the basic aim of promoting their human and civil rights (Beresford, 2002). Policy and

research discourses on disability, therefore, have changed significantly over recent years to focus on rights, social inclusion and investment in structural change (Waddington, 2006; Priestly et al, 2010).

A number of disability studies have been underpinned by what has been referred to as the 'emancipatory' model, which stresses that the main outcome of research should be social change and attempts to overcome disablism affecting the lives of disabled people (Barnes and Mercer, 1996). These research endeavours have been strongly influenced by the social model of disability and linked to the wider disability movement (Walmsley, 2001). Certain commentators have claimed that the development of the social model of disability has promoted different ways of undertaking research with people with learning disabilities (e.g. Chappell et al, 2001). The aim of the empirical work informing this thesis was not to seek to promote immediate social change for this marginalised population. By accessing the men's accounts, it was hoped that awareness of the barriers and social inequalities they face, could be raised. As such, the research is linked to the social model of disability, but it cannot go as far as to say it can overcome disablism. However, the research here, aimed to provide men with a voice, that otherwise may not have been heard. It endeavoured to contribute to producing knowledge through highlighting the social disadvantage experienced on a day to day basis by the men, which could, in turn, contribute to social change.

In taking up the challenge of this research, the responsibility was to facilitate an exchange of thoughts, and develop a rapport between the academic researcher and marginalised individuals (Atkinson, 2005). This approach also demands that the researcher is aware of traditional positions of power: with the researcher being viewed as a powerful expert, with the participant assigned to a passive role (Northway, 2010).The approach endorsed within this chapter is founded on the premise that the lives of people with learning disability matter, and that by revealing their stories light can be shed on otherwise neglected or concealed areas of social life (Atkinson, 2005). Historically, disabled people have been excluded from the research process, being viewed as 'unable' to participate (Northway, 2010). However, collective narratives and anthologies from people with learning disabilities themselves, such as *Positive Tales*, according to Atkinson (2005), for example, demonstrate that this group of people are capable with assistance, of articulating their stories in their own words. Therefore, the stance of this research was aligned to ways that could best develop a partnership with the men, to promote their 'testimonies', through acting as a sympathetic, supportive, non-disabled researcher (Goodley, 2001). Active involvement of men with learning disabilities was supported through their involvement as steering group members and gaining men's accounts through semi-structured interviews.

Further dimensions to social divisions

In addition to considering the impact of disability, in order to provide more

pervasive knowledge of how men with learning disabilities themselves experience their social world and its impact on their health, two further social divisions, namely relative poverty and gender were explored, in addition to considering the impact of disability. As highlighted in chapter three, adults with disabilities are more likely to face health disadvantages associated with lower socio-economic position, such as lower incomes and lower employment rates, compared with non-disabled people (Chapman et al, 2008). Therefore, an exploration of men's experience and perceptions of poverty was seen as a further crucial dimension to understanding how such social inequalities affect the health of this group of men. In addition, as chapter four demonstrated, the concept of masculinity provides a further crucial dimension to understanding how men with learning disabilities experience and perceive health. Gaining men's accounts of the impact of gender on their health would open up such issues as the health damaging behaviours associated with being male. The research was therefore designed to explore the impact of these three major social divisions.

Methodology

Qualitative methodology

Understanding how men with learning disabilities make sense of their social world and the ways in which their health is affected, demands a mode of inquiry that facilitates research participants' full expression of personal experience and perceptions. Becker and Bryman (2004:57) illustrate this perspective as follows:

It would be acknowledged that systematic reviews, randomised control trials and other experimental designs provide the most appropriate form of evidence on 'cause and effect', while ethnography, and other qualitative methods provide the most appropriate form of evidence on 'experiences and processes', especially as understood by the respondents themselves.

The potential benefits of a qualitative approach include the opportunity to access meanings, perspectives and interpretations from different groups of people (Willig, 2001). Adopting a qualitative approach therefore, provided me with the opportunity to facilitate a deeper understanding of how the men with learning disabilities, themselves, perceived and experienced health (Silverman, 2000). The standpoint of this thesis is that qualitative research methods offer a more effective means by which to explore issues around how men with learning disabilities regard the impact of disability, relative poverty and gender on their health. In exploring these issues through the lives of men with learning disabilities, the thesis addresses an imbalance in the tendency of research in this field to concentrate on the experiences of women with learning disabilities (National Health Screening Programmes for Disabled Women, 2006; McCarthy and McMahon, 2008; 2009). In comparison, there has been relatively little qualitative research that has explored men's subjective accounts of their lives and the experience of health.

Pessach (2009) claims that within qualitative research, the researcher is also determined to reduce the 'distance' between the researcher and the participant. This acknowledges that the relationship between researcher and participant needs time and consideration to develop. For example, the researcher at the initial stages of research has the knowledge and information regarding the aims and purpose of the research, which needs to be fully explained to the participant. The researcher needs to nurture the relationship in further ways, for example, by creating a welcoming environment in which the participants are then willing to share their experiences (Miller et al, 2009). Overall, the researcher needs to try to develop a relationship that is informal, anti-authoritative, and that demonstrates feelings of empathy towards the participant (Taylor and Bogdan, 1998). From a feminist perspective, efforts to overcome the oppression of certain vulnerable populations, have seen some researchers actively try to address the difference in the relationship between researcher and participant, by negotiating different roles in the research process, in order to promote dialogue (Brayton, 1997).

In terms of people with learning disabilities, a variety of qualitative research methods have been adopted that enable people with learning disabilities to become more meaningfully involved in research (Walmsley and Johnson, 2003). These have included life histories and narrative work (Atkinson, 2005), ethnographic approaches (Goodley, 2000) and participatory approaches (Kiernan, 1999 and Northway, 1998; 2000b; 2010). Terms, such as 'inclusive', and 'shared', are now in common use in relation to research

with this population (McClimens, 2010). Contemporary research endeavours that involve people with learning disabilities recognise that this group of people can be key participants, accepting that individuals are the best authority on their own lives, experiences and feelings (Dowse, 2009).

Elements of a participatory approach

In the context of qualitative research, the basic premise, on which the participatory approach is founded, is that marginalised groups have specific knowledge of their own lives that needs to be valued and acknowledged (Katsui and Koisten, 2008). A participatory approach therefore aims to involve previously excluded and vulnerable groups as active partners in the research process (Malone et al, 2006). Participatory research has also been developed as an approach that can facilitate the involvement of disabled people (Khanlou and Peter, 2005) and is seen as one way that people with learning disabilities can be partners and collaborators within different stages of research (Walmsley and Johnson, 2003). This also involves finding more and different ways of forming partnerships with the individuals themselves in the research and not simply forming partnerships with organisations that individuals may be part of, such as advocacy organisations (Chappell, 2000).

Northway (2010) argues that participatory research not only focuses on the technical aspects of knowledge production, but on the values and motivations of those who undertake such research. As Northway (2010) states, whilst participatory research can be undertaken in different ways, it

has certain common features, such as a commitment to changing the balance of power by the researcher; the centrality of the community in question to the research; a different role for the researcher, from that in more 'traditional' forms of research; active participation of the community in question in all stages of the research; the production of 'useful knowledge' and a commitment to action. Getting to know individuals and building a rapport is a key element of this approach (Walmsley, 2004), alongside endeavours to 'level out' the relationship between the researcher and the researched (Malone et al, 2006). Participatory research has also begun to be understood as an approach which can occur in different forms and does not need to include participants in all components of the research process (Conder et al, 2011).

Whilst acknowledging this study did not contain all the features of participatory research, as indicated by Northway (2010), it did incorporate certain key aspects. Men with learning disabilities, as part of the learning disabled community, were the central focus of the research. The study set out to involve two different groups of men with learning disabilities in different, but specific aspects of the fieldwork. One group of men formed a steering group who were involved in the pre-field work stage and in follow-up meetings concerning the fieldwork. Working alongside this steering group and the influence it had on the process of the research, assisted in equalising the research relationship. The other group of men were participants through semi-structured interviews. However, their 'user' status did not predetermine whether the men participated in this study and none of

the men were receiving any professional health intervention from specialist

learning disability health services at the time of being involved in the

research.

Endeavours to 'tilt' the balance of power away from myself as researcher in

the course of interviewing took a number of forms. Additional time through a

series of introductory meetings to develop a relationship with the men, the

production of accessible pictorial documentation and use of simplified

language, were key aspects of the interview process. The useful insights

produced from the research, and the suggested forms that dissemination

back into the learning disabled community could take, were other elements

aligning the study to a participatory approach.

My role, as researcher, was therefore to acknowledge cognitive and

intellectual difficulties associated with people with learning disabilities and to

recognise the different stages within which hierarchal relations of power can

exist between researchers and participants (Pessach, 2009). Interviewing

participant's means being conscious of and expecting various forms of

power to move back and forth between the researcher and the participant

(Nunkoosing, 2005),for example, participants deciding where they want to

be interviewed and how and when they wish to answer questions.

Therefore, initially I held the power to determine the type of involvement, but

during these stages, I had to ensure a clear collaborative arrangement had

been established to 'tilt' the balance of power away from the researcher.

Semi-structured interviews

As Kvale and Brinkman (2009) have argued, the interview is a conversation with a structure and purpose, in that it goes beyond a spontaneous exchange of views, with a careful questioning and listening approach. Interviews can take many different forms. They can vary from structured and formalised interviews which involve asking the same questions in the same format to every participant. For example, in responses to a pre-set questionnaire, and possibly with largely pre-set responses; to less structured interviews that enable the participant to provide a fuller account of what they want to communicate, in a way they want to express it (Iphofen et al, 2009). In this way the semi-structured interview allows the researcher to access how respondents organise their personal stories and understand them through the commentaries they create to explain and justify their life experiences (Silverman, 2011). A key strength of the semi-structured interview, therefore, is its capacity to enable and encourage self reflection among interviewees, leading to the telling of stories that enable others to understand and theorize the social world (Silverman, 2011). Kleinman (1994:43) illuminates this point further:

Respondents may reveal feelings, beliefs and private doubts that contradict or conflict with "what everyone thinks", including sentiments that break the dominant feeling. ...In other cases, interviews will discover the anxiety, ambivalence and uncertainty that lie behind the respondent's conformity.

The semi-structured interview also enables the interviewer to employ an interview schedule as a guide to key issues they wish to explore, while allowing the interviewer to follow up other potentially significant issues as they arise (Silverman, 2011).

A number of researchers have utilised semi-structured interviews with people with learning disabilities. Early work by Booth and Booth (1994; 1998) with parents who had learning disabilities, adopted semi-structured interviews to draw out experiences of parenthood and having a learning disability. Likewise, McCarthy (1998) conducted semi-structured interviews with women with learning disabilities regarding their sexual experiences, and more recently Wheeler (2007) interviewed men with learning disabilities about their sexuality and sexual identity. Other topics have also been tackled through the use of semi-structured interviews with this group of people. Ellem et al, (2008) for example, interviewed ex-prisoners with learning disabilities about their experiences of custodial sentences. Visual aids have also been adopted to supplement semi-structured interviews, for example using photography for life story research (Aldridge, 2007). The semi-structured interview has come to be viewed as a way in which participants have considerably more degree of control over what they share than in tightly structured pre-set interview schedules (Wheeler, 2007.) This thesis uses semi- structured interviews, that draw upon men with learning disabilities 'personal stories' (Graham, 1983), supplemented by visual aids as required, to begin to identify their experience and perceptions of the material and psychosocial environments that influence their health.

The practitioner as researcher

I enrolled as a PhD student with previous experience as a community nurse for people with learning disabilities. My previous practice experience gave me insight into the ongoing health concerns and concomitant health inequalities many people with learning disabilities and their families can be exposed to. This in turn, influenced my desire to explore the impact of such inequalities, and the subsequent choice of methodology associated with the promotion of inclusive research strategies. In these ways I endeavoured to marry my previous practice experience to the role of researcher.

Whilst not practising at the time of undertaking the research, I was still registered and accountable to a regulatory professional body, which requires me to reflect on my personal and professional beliefs (Northway, 2000a). Thereby, whilst I predominantly adopted a researcher role, I still needed to be cognisant of the values and principles associated with my registered practitioner status and the way in which this could affect interaction with the participants.

From a pragmatic perspective, my previous position as community nurse in the locality helped facilitate access to the local authority, through my professional credibility with senior gatekeepers and service staff. As a partial 'insider', I also had knowledge of organisational culture and informal organisational structures. However, my position brought potential disadvantages as well. Notably, it could bring with it the risk of making

assumptions based on insider knowledge (Coghlan and Brannick, 2010). To overcome this, I was mindful that pre-existing assumptions regarding the local authority as an organisation could be a distraction and therefore tried to ensure that these would not cloud my judgement as the researcher (Northway, 2000a). None of the men interviewed knew me when I had practised as a community nurse, but knew I had been a nurse previously.

Fieldwork

Gaining Access

Access was gained in the same way to the two different groups of men with learning disabilities participating in the research. The steering group constituted the first stage of the research, in which men with learning disabilities were involved. They were recruited from a local advocacy organisation, which I was familiar with as a practitioner and which I knew contained men who had been able to participate in other research projects. I wrote to the Director of the organisation detailing the overall aims of the research and the type of support and assistance I required from a steering group (see appendix 1). I also asked if I could liaise with a worker at the organisation who could help recruit volunteers for the steering group. Once access was granted, I met the designated worker to brief her regarding the nature of the steering group involvement and provided her with an information sheet on the role of the steering group (see appendix 2). She then introduced me to four potential members. I checked and further discussed their understanding of what being part of the steering group

meant to them. I was reassured that they had been fully informed by the worker, that they had the capacity to contribute, and were happy to do so.

Steering group

It was not deemed necessary to undertake the process of gaining informed consent from the steering group members; primarily because they were not part of the data collection process. Their main role was to provide guidance and advice on key documentation and feedback on the main findings and dissemination. Steering groups have increasingly been utilised in the preliminary stages of research and act as a supervisory group overseeing research projects (Rapport et al, 2008). Research has also shown how if the partnership is carefully established between researchers and people with learning disabilities, then this group of people can be involved effectively in many stages of research, from design to dissemination (DH, 2006).

At our first meeting, we discussed again the nature of their involvement as steering group members. I provided each of the men with a draft of the information sheet for interviewees (see appendix 3), the consent form (see appendix 4) and the interview schedule (see appendix 5). The men were immediately able to offer me advice. We went through each document in turn. I listened as each of them made suggestions as to how the documentation could be improved. For example, they felt one picture on the consent form was misleading. There was also a general consensus that two of the pictures on the information sheet could be amended to aid

understanding. One of these pictures, for example, depicting a conversation could be improved by using a more lucid picture. The men also made suggestions about altering some of the wording on the information sheet, because it was too complicated, for example, replacing 'confidentiality' with 'safe and locked'. The men made a number of other suggestions as to how to improve this, such as increasing the font size of the written language. I agreed to make the changes in line with their comments and to return the following week with the amended documentation.

The steering group was reconvened the following week with the amended documentation, which the men were happy with. We then agreed to meet again when I had undertaken a number of interviews, to review the process and to feedback how the documentation they had helped develop was being utilised. A further meeting was planned to review and feedback the findings. At this stage, the suggestions made by the steering group were helpful, not only in relation to specifics of written and graphic material, but provided valuable guidance for me generally, as they indicated verbally the use and style of language that I would need to employ with the interviewees.

Recruiting interviewee participants

Having gained ethical approval from the appropriate University body, I then wrote to the Assistant Director of Adult Services within the Local Authority, introducing myself and explaining the aim and purpose of the research (see appendix 6). I also asked if he could identify a key service manager(s) who

could identify a number of gatekeepers across the locality who worked with

men with learning disabilities and who would be able to identify a pool of

potential volunteers. I then conducted a presentation to the nominated

service manager, explaining it would be men with mild to moderate learning

disabilities who I would be looking to recruit to the study. This process

helped to identify specific Local Authority schemes, such as social

enterprises and employment services, where men with mild to moderate

learning disabilities were likely to attend. The service manager then gave

me permission to approach these schemes directly. I subsequently

undertook a presentation to two teams of staff describing the aims and

objectives of the research, and the inclusion criteria. All these workers had

regular contact with a caseload of men with mild to moderate learning

disabilities across the locality. I left information sheets (see appendix 3) with

these staff members to facilitate their initial discussions about the project

with men who they worked with and then asked them to assist my

subsequent introduction to potential participants. I explained that I was

unable to provide a financial payment for this type of research.

My target sample for the study was twenty men. Purposive sampling was

undertaken (Bryman, 2004) as a strategy to access individual men who I

hoped would best be able to participate in the research. I emphasised that

the individuals must not be currently residing in a health service provision, or

receiving health interventions from Specialised National Health Service

Learning Disability Services. This decision was based in part on wanting to

draw men from a cross-section of backgrounds across the city and not

wanting to interfere with any current health treatment or interventions the

men may be receiving. I explained that I also wished to pilot my interview

schedule with two men, in addition to a target sample of twenty other men.

The workers were therefore instructed to explain the pilot interview to the

men and ask if they wished to be involved and how this would help. Two

men decided to take part in pilot interviews, which were then arranged. The

men were asked where they wished the pilot interview to take place. They

decided that their homes were the most comfortable place for me to talk to

them and pilot the interview schedule, and both of these pilot interviews took

place there. Every effort was made to explain to these men that they would

be helping me to try out questions that would then be put to other men and

in this way were helping with the preliminary stages of the research. Despite

my best efforts, I was not sure if the men fully understood the concept of

pilot interviews. This pilot process reinforced the demands of dealing with

subtle concepts with this group of people. It also reminded me that each

individual would have their own way of communicating, which I would need

to 'tune into' as effectively as I could, to explain the nature of involvement.

Introductory meetings

Prior to the interviews commencing, a number of introductory meetings with

the participants took place. These were in different settings, familiar to the

participants and were mostly on a one-to-one basis. The initial purpose of

these introductory meetings was to provide the worker with an opportunity to

introduce me to the potential participant and for me to clarify what the

intermediary had said about the research. This enabled me to ensure that

the individual participant had made the decision to volunteer of their own

volition and to develop a rapport on my own with the men. During the

process of recruitment, I was acutely aware of the tendency towards

acquiescence associated with people with learning disabilities (Kiernan,

1999) and the need to counter this. A further purpose of these meetings was

to provide the additional time required to get to know the men. This was in

addition to providing accessible information to them, to try to ensure they

were fully informed about the research, their potential involvement and had

ample opportunity to withdraw, if they wished. In most cases, I had three

introductory meetings with the participants. All of the interviews, based on

informed consent, took place as soon after these introductory meetings as

was possible, as a means of building and maintaining rapport and for the

topics to remain 'fresh' in the minds of the participants.

The first introductory meeting involved three men who were attending an

evening workshop. I met with them at the beginning of the workshop to

explain more about the research. They appeared to have some idea of what

the research was about and how they could become involved. Although

these men were aware of each other's potential involvement, at this stage,

no decision had been made about their actual involvement. I contacted each

of them separately after this initial introductory meeting to ensure that no

other man would be aware of their involvement. They agreed to me meeting

them individually at their homes to discuss further the nature of the research

and what was involved. This meeting allowed me to chat generally with each

man, getting to know their communication style and then going through the information sheet (see appendix 3), further clarifying their understanding in relation to the aims of the research. I also established that their home was their preferred place to be interviewed. In order to explain the time span and nature of the participant's involvement within the research, I highlighted to all the men that after these initial meetings and if they were then happy to be interviewed, that would complete the involvement in the research process. As Northway (2000b) states, engaging in participatory research with people with learning disabilities, demands that the researcher is clear about the terms of involvement. These introductory meetings were time consuming, but necessary to ensure that it was ethical for men to proceed, to build a rapport, and enable a more relaxed and confident relationship to develop, as is aligned to the participatory approach (Walmsley, 2004).

However, not all of the introductory meetings were straightforward. During one introductory meeting with two potential participants, the presence of a dominant worker appeared to affect the way in which the men understood the information regarding the project. The worker continually talked over the men and on a number of occasions seemed to coerce the men into taking part. As a result, I stopped this encounter and arranged to meet individually with the men. One of the men had clearly become anxious and the circumstances of the previous meeting had not allowed him to process the whole meaning of the research. He decided there and then not take part. I arranged a one-to-one meeting with the other man at another time, which allowed me to talk through the aims of the research and how the interview

would take place. For this particular man the university was considered a suitable venue, away from his distracting home and work settings. However, the fact that we met in the researcher's place of work (university) gave the man the impression that he was there to learn something and I had to work hard to explain that it was his life and thoughts and feelings about health which I was interested in. He subsequently decided not to be involved. This highlighted some of difficulties of relying on intermediaries to introduce me to the men and issues related to the choice of setting for these meetings, as well as the importance of seeing men on an individual basis immediately after the introduction. After a few days I contacted their key worker and was informed that they did not want to take part, and had used the phrase: "*It's not for me*". This response reassured me that they had gone through a decision making process, which resulted in them choosing to opt out (see table one) below for final numbers of participants.

Table One   Numbers of participants included in the research

Total of men approached by workers	Number of men declined prior to introductory meetings	Number of men declined after introductory meetings	Number whose involvement was not considered appropriate by the researcher	Total participants interviewed
30	5	3	2	20

Selection

From the pool of thirty potential participants provided by the local authority workers, ten individuals did not take part (see table one). I was informed by the intermediary that five men did not want to take part in the research prior

to me meeting them. During the introductory meeting it became apparent

that the involvement of two men was not appropriate. In one case, after

going through the information sheet and using pictorial cards to support the

dialogue, it was evident by the man's responses that he was unable to grasp

the purpose of the research. I decided it would be unethical to include him in

the research and that his key worker, who knew him well, would inform him

of this. Another man had a very prominent speech impediment, which was

difficult for him to overcome in conversation and he appeared to become

increasingly nervous during our introductory meeting. I found it difficult

explaining to him that for ethical reasons, the interview might cause him

further anxiety.

Sample

Twenty men were finally recruited to the study. They were aged from

eighteen to seventy years of age. Over half of the men lived independently,

while other participants lived with a variety of other people, such as their

parents, with a friend, in supported living options, one with his girlfriend and

daughter, and one with his wife. This represented a cross section of the

different living arrangements in the community that people with mild to

moderate learning disabilities can have (see appendix 8).

None of the participants or their personal circumstances were known to me

as a practitioner. Such a relationship may have impacted on our relationship

and interactions as researcher-participant and would also have required me

to reconcile previous assumptions and experiences regarding the participants. The values researchers bring to the research are shaped by their own social and historical background (Hammersley and Atkinson, 1998). Previously working within a National Health Service provision, with a focus on assessing needs and overcoming deficits, could have clouded my perception of the capacity of the men to share their experiences and perceptions, as participants. Not having previously worked with any of the participants, at the time of conducting the research, I introduced myself to the participants, as a researcher.

Conducting the interviews

All of the interviews were conducted alone with each man, on the basis of signed informed consent at the outset. They varied in duration between approximately forty minutes and one and a half hours. In all of the interviews, I asked for their permission for the interview to be recorded and this was provided on the consent form. The introductory meetings with all the participants had allowed me to become familiar with their level of comprehension and to be exposed to how each participant communicated verbally and whether we both felt, for instance, that the use of flash cards (pictorial accessible information) would assist the interview (see appendix 7). These meetings had also allowed me to build a rapport with the participants that carried through to the interviews thereby developing an atmosphere that would be conducive to open and honest communication (Silverman, 2011). The interviews took place in a number of settings. The

choice of site for interviews is important as it can influence the dynamic between the interviewer and interviewee, as well as the direction and content of the conversation (Sin, 2003). All the men who lived independently were interviewed in their own homes. The men who lived with their parents chose to be interviewed at their work setting; a suitable and quiet interview room being allocated on each occasion. They decided that their home setting might be distracting as other members of the family were likely to be present.

It is only relatively recently that accessible pictorial information has been used in interviewing with people with learning disabilities, along with a number of symbols and photographs that describe different topics (Ponceas and Murphy, 2007). I used symbols and photographs accessed from sites found through Google and more specialised material through www.easy-read-online.co.uk/2010.

Eight out of the twenty men were able to maintain a conversation without such information. Four of the men were able to be interviewed with little reference to the cards, whilst the remaining participants (8) found the flash cards helped them to process questions and facilitate a response. All the flash cards were laid out in front of the participants before commencing the interview. For the interviews conducted in the participant's home, I had to be flexible when there was no coffee table or obvious place to position the cards. On occasions the cards could be a distraction as I had to carefully

integrate my question, calculate whether the response required further verbal prompting or the use of the card. Once a question was asked, in some cases additional time to process the question was required. I tried to rephrase the question before relying on the card for prompting to help draw out the meaning and experience related to the topic under question. All the men were asked to rate their health from excellent to poor, in which case the pictorial cards were used with all the participants. This required the men to choose one of four symbols to categorise their health (see appendix 9). In most cases the men were able to point with some assurance to how they rated their health. Other men were different, needing more time to deliberate and further time to process their response, changing their initial response and then settling on their answer by pointing to a different symbol.

As with all interviews, flexibility on behalf of the researcher was required. The interview schedule acted as a guide to shape the conversation and I was able to adapt to the individual verbalisation of each participant (Kvale and Brinkman, 2009). The interview schedule covered a number of themes that formed categories for questioning. Although the participants did not have an interview schedule in front of them, the categories were broken down (placed in brackets on the interview schedule), into simplified explanations, before commencing that area of questioning. This helped explain to the participants the different topics the questions were about to cover and encouraged them to talk about these areas in their own terms (see appendix 5).

At the start of each interview, the men were asked some basic demographic information, for example, their age and who they lived with. Some of the men were not able to provide this. They were able to give the name of a suitable person, either relative or carer that I could contact with their consent, in order to obtain this information. Along with essential interviewer techniques, such as listening, paraphrasing and sequencing questions, I was conscious of having to use clear, simplified language and be prepared to modify this with each participant. Finlay and Lyons (2001) reported that many individuals with learning disabilities are able to self report through interviews and open questions, as long as complex concepts are avoided and sentence structure is clear. As people with learning disabilities are a group of people with varied cognitive and communication requirements, I had to be careful not to use overly complex grammatical phrases and abstract concepts, using the accessible information to facilitate the discussion when required (see appendix 7). Different images were selected that were associated with these notions (see appendix 7). I dealt with the concept of masculinity, for instance, by reminding the men what we had discussed about this topic in our introductory meetings and where appropriate, recalling how they had thought about this topic. For instance Conner referred to 'being a man' as "*some men build their muscles up, and others do it do be good at sport*". I endeavoured to use the same approach to convey the concepts of disability and poverty. In terms of disability, Ivan referred to this as "*things that affect my live" and* Jack initially thought about poverty in the following way*: it's like how I feel about where I live and that".*

Whilst not all of the participants required these visual reminders, it is recognised that people with learning disabilities may have difficulties verbalising responses that are content specific (Lloyd et al, 2006). Therefore extra time has to be afforded for individuals to process these ideas and respond, in order to build the conversation. This demands that the interviewer is also self conscious of their own communication style and aware of the quality of interview schedule (Lloyd et al, 2006). In keeping with a participatory approach, providing the additional time and accessible information to be responsive to the participants' individual communication styles, facilitated their involvement. In so doing it shifted the control away from me as the researcher and assisted the participant's active involvement.

At the beginning of the interview and subsequent periods during the interview, I reminded the men we could have a break at any time. It was the case that three of the men required a break during the interview. One man, Mark, requested this and the other men, Sam and Oliver, I prompted about having a break as they were losing concentration, 'drifting off' and becoming less communicative during our conversation. After a suitable interval, I checked if they were still happy to continue. Following their break, I had to work hard to recapture the flow of conversation.

Ethical Considerations

Ethical Approval

The research proposal underwent stringent procedures before being

granted ethical approval. Arrangements were in place within the School of Health Studies at the University of Warwick for ethical scrutiny and approval of my research proposal/ upgrade document. The research was scrutinised by a cross departmental review, which reported to the Departmental Research Committee.

I then submitted an outline detailing the research to the Chair of the relevant Local Authority Ethics and Governance Committee. This was accepted and permission granted for me to proceed and make contact with the key gatekeepers.

Informed Consent

Miller and Boulton (2007) argue that experiences of agency, power and risk shape qualitative research encounters. The notion of acquiring consent that is informed, presupposes that potential participants possess an understanding both of the nature and aim of the research and how it will be undertaken (Miller and Boulton, 2007). Thus, undertaking research with participants with expressive language and intellectual difficulties, such as people with learning disabilities, is not straightforward (Condor et al, 2011).

One approach designed to overcome this has been to seek consent by proxy, in terms of another party, such as a carer providing consent on behalf of the individual. However, this in itself can present difficulties as the

purpose and aim of the research can be mis-communicated between the intermediary and the potential participant (Rodgers, 2001). Furthermore, this approach overlooks the individual's capacity to comprehend the purpose of research and can further perpetuate the disempowerment and marginalisation of vulnerable groups (Proctor and Rosen, 2008). I made the decision not adopt this method, seeing it as necessary for me to take responsibility for providing men with adequate information regarding the study and for ensuring that informed consent was provided (McClimens and Allmark, 2010). This stance was in keeping with valuing their contribution and valuing the men as autonomous individuals. As the necessary additional support, time, and pictorial information was put in place; the men had the capacity to make a rational decision to take part (see appendix 3 and 4). All the men taking part in the research had mild to moderate learning disabilities. This was not to preclude the importance of the topic to those with more severe disabilities, with whom it is acknowledged gaining informed consent is also not straightforward and can be even more difficult. As highlighted in chapter one, as this area of research has not been previously explored, the aim was initially to test and base the research on the viewpoints of those men with mild to moderate learning disabilities, before planning the application of the topic with those with more severe disabilities.

Process undertaken to gain informed consent

The notions of respect for people and their autonomy to make decisions are

fundamental to informed consent (Beauchamp and Childress, 2001). Whilst more inclusive research has taken place with people with learning disabilities over the last decade, nonetheless, obtaining consent from individuals to enable them to participate in research, when their mental capacity is impaired remains a challenge (McClimens and Allmark, 2010). Whilst people with learning disabilities are a heterogeneous group, those with a milder learning disability are generally considered capable of understanding the purpose of research projects and providing informed consent (McClimens and Allmark, 2010). Nevertheless, being aware of the potential for their acquiescence helped me ensure I allowed the necessary time over the introductory meetings and all subsequent meetings, for the men to provide informed consent. As the researcher I had to make a judgement that the participants had the capacity to give consent and that their consent did indicate that the individual wanted to participate.

As previously highlighted, I met all the participants in the majority of cases on three occasions after the initial meeting with the intermediary, before consent was given and the interview proceeded. In this way preparation for gaining informed consent was an ongoing process, undertaken throughout these encounters. On each occasion, I was assessing their level of communication ability and capacity to give consent. In some cases, this required referring to the information sheets more than on other occasions and clearly specifying what their involvement in the interview entailed (see appendix 3). Being more familiar with the aims of the research at this stage, I recognised I held a degree of power on these occasions. However, in an

attempt to facilitate the relationship, I pointed out that they had the power to refuse to answer any question and that they could stop the interview or withdraw from the study at any stage and their data would not be used. I stressed that we would be having a conversation about their life and different aspects of their lives that can impact on health. When needed, I would refer to the respective picture and point in the information sheet and allow time for this to be processed. In this way, I was trying to convey also that no harm could come from their participation and that sharing their perspectives could help to produce a deeper understanding of social inequalities affecting the health of other men with learning disabilities. I had to break the concept of social inequalities down, explaining carefully and referring to things such as whether the men had a job; where they lived, how they felt about that and whether they felt they had enough money to buy what they wanted. I tried to take account of individual differences and to ensure that the individual signed at their own free will and providing the opportunity to clarify any points they wished. In a number of cases the participants sought clarification on certain aspects, such as; "*So you are looking after that [tape recorder] safely*"... "*I don't mind not being paid*"... "*So it is about my health and life*". These responses allowed me to provide further clarification and reassured me that the men had comprehended these aspects. I reminded them that they could stop the interview at any stage, asserting that they had the power to do this whenever they wished. At this stage I checked again that the participants were happy and consent had been given before turning on the digital recorder and proceeding with the interview.

Maintaining Confidentiality

Part of an ethical approach to research is to take steps to protect individuals from harm, through ensuring anonymity (Baez, 2002) concerning personal details and that measures are taken to secure data. This meant ensuring transcripts, research notes and anything related to personal information remained in a locked filing cabinet, in a private office, when not in use, or stored on my personal computer that was password protected. The names and addresses of the participants were stored separately and did not appear on the transcripts and pseudonyms were used on all research notes and interview schedules for participants to remain anonymous. Any names, places, or information that could be linked to the identity of the participants were changed on all documentation. This was explained and reiterated during all my meetings with participants and was reflected in the consent form (see appendix 4) and the information sheet (see appendix 3). I was conscious of having to take extra time to explain what this meant, referring to the information sheets for visual guidance when required.

Breaking confidentiality

I also made every effort to explain clearly that there may be circumstances under which confidentiality could not be maintained. These circumstances would be in the event that they divulged they were being harmed or were at risk of potential harm. I explained that I would have a duty to pass on any information to the necessary authority. It was also the case that if the participants had any cause to complain about the research process, this

would be passed onto to the appropriate authority too. It was made clear to

the participants that if at any point during the interview the participant

became distressed the interview would be terminated immediately. The men

were given the opportunity to resume the interview at a later stage if they

wished to. In these circumstances both my research and professional code

of ethics would apply (Ellem et al, 2008). I was nervous about the potential

impact that informing the participant about the possibility of breaking

confidentiality would have on our relationship and trust. But no participant

withdrew when informed about this. In the event, these precautions were not

called on as no such issues arose during the research process.

Post field work phase

Data analysis

I decided not to use computer assisted qualitative data analysis software

(CAQDAS) to analyse the data. It has been suggested that when using this

software there is a tendency for code and retrieval processes that support

CAQDAS to fragment the textual materials, resulting in the risk of losing the

narrative flow of transcripts (Weaver and Atkinson, 1994). I therefore chose

not to use CAQDAS, as the pre-existing lack of fluidity that can exist in

conversation with this particular group of men, meant that the meaning of

dialogue would be at increased risk of being lost, undermining

understanding in the process. As Alcock and Iphophen (2007) argue,

CAQDAS can also fragment data into chunks, which are then retrieved and

put together into groups of related fragments, which run the risk of data

being decontextualised. Having an awareness of the context is important to qualitative research and the potential for this to be altered would be disconcerting (Fielding and Lee, 1998).

I therefore immersed myself in the data, which was manually analysed. In keeping with most forms of qualitative analysis, the data analysis began with coding (Bryman, 2004). This was divided into three consecutive stages, open coding, axial coding and then selective coding (Miles and Huberman, 1994). With open coding themes are identified, compared and then categorised across all the transcripts. To do this, all the transcripts were read through and reread a number of times. As each one was read, I made notes in the margins on printed transcripts as I went along, beginning the open coding stage. Different amounts of data were then cut and pasted as different coherent comments emerged from the accounts, which were then colour coded. Axial coding is the process of making connections between the identified categories. To facilitate this stage and to allow similar themes and connections to be elicited across the accounts, the research questions were used as a reminding framework. Field notes and memos made during the research were also compared with the interview transcripts to check for additional or confirming information and helped with the analysis. This acknowledges that data collection can also draw on unconscious as well as conscious elements (Corbin and Strauss, 2008). After the two initial stages of coding, I decided to structure the analysis using selective coding, which is where core themes are finalised, a core theme being the central issue around which all other categories and relationships between them are

integrated. This meant identifying the relationships between core themes and how they were integrated in men's accounts. This was determined by using the three broad areas related to experiences and perceptions of disability; relative poverty and masculinity and selecting key comments reflecting the impact on health, as demonstrated through the accounts. This analytical process also enabled me to explore the significance of how different social dimensions impacted on the health of men with learning disabilities living in different settings.

Steering group

In addition to the preliminary meetings during the pre-field work stage, I met with the group on two further occasions. This was to update them on the progress of the research process, ensuring individuals' confidentiality, and to feed back once interviews had been conducted. I also reminded them of the timescale for completion of the research. In the first meeting the men then made suggestions as to how I could disseminate the work, acknowledging themselves the potential value of sharing the work with others in the learning disability community (Northway, 2010). We planned to meet again once I had analysed the data and had the findings to share with them. At that stage we could continue the discussion on dissemination.

The final meeting with the steering group as part of the fieldwork process was convened to feed back the findings of the research (see appendix 10). In the event, this meeting was with two of the original steering group. The

men listened carefully as I went through themes from the anonymised findings. They were able to corroborate some of the findings with their own experiences, in particular regarding harassment and work experiences. I was reassured by their comments and feedback, which in a small way helped confirm some of the specific findings from the research. In terms of dissemination and following on from their suggestions, we agreed to develop an accessible summary of the findings for the local authority once the thesis was completed. We also had a preliminary discussion regarding a network event, to feedback to the wider male learning disabled population in the locality (see appendix 11).

Potential limitations of the empirical study

It is acknowledged that the analysis is drawn from a relatively small sample of men from an urban setting, which could not be representative of all men with learning disabilities and may be dissimilar to those living in rural areas. Nonetheless, it is hoped that the research raises significant issues regarding the impact on their health of social divisions faced by this population of men. Gaining insights into the social world through interview encounters raises issues of 'truth' and 'reliability'. As Nunkoosing (2005) has argued, the intention behind the qualitative interview is to connect an external world of events to an inner world of thoughts and emotions as constructed by the interviewee (Nunkoosing, 2005). However, the interview does not solely represent the viewpoints of the participant, as the dialogue is co-constructed between researcher and participant (Schostak, 2006). The researcher has

the responsibility to portray their interpretation of the accounts to others, while endeavouring to make connections to all that they have heard. Moreover, the interview process as a whole includes the researcher's memories of time spent with the participants and how the research data was gathered, forming a part of the meaning and therefore the analysis (Parker, 2010). The interviews were also not just gender neutral conversations between an interviewer and interviewee; they involved a dialogue between two men. As demonstrated through other encounters between men, masculine identities are constructed and conveyed through what is revealed through the interview process (Oliffe, 2009). Given the men did have an understanding of masculinity, what the men said could not only be influenced by what the men thought they should say as men, but in addition by my male researcher identity. As a non-disabled researcher undertaking research with a marginalised group of disabled men, I was conscious that through their involvement in the research, I should try to ensure that they would not be further disadvantaged in any way. This demanded that I constantly reflected upon the way in which the men were involved and could potentially benefit from the research in the future (Northway, 2000a).

Conclusion

This chapter has explored the methodology employed in the study of the perspectives and experiences of men with learning disabilities. This has been informed by perspectives derived from interpretive sociology, qualitative research with a focus on disability, a participatory approach, and

consideration of multiple social divisions. It has sought to demonstrate why and how the methodological stance has given primacy to drawing on the accounts of the men themselves of the impact of key social divisions on their health.

The chapter has detailed how two different groups of men with learning disabilities were involved in the research. As steering group members, the men were able to guide, check and provide insight into key documentation before it was utilised. They also provided feedback after a number of interviews had been undertaken and confirmed some of the research findings and assisted with plans for dissemination. In this way the steering group enabled the researcher to carry out the interviews and analysis more effectively. The second group of men participated in semi-structured interviews, which was the main data collection tool for the research.

In undertaking interviewing, a participatory approach informed my work as researcher, in my endeavours to develop a meaningful rapport and relationship with the men. This was crucial to be able to access and interpret the men's experience of social divisions and its impact on health. The chapter has also examined the additional steps I took to be responsive to intellectual disabilities of the participants and to tilt the balance of power between the researcher and participant, more in the participant's interest. The chapter has also reflected on the requirements involved in gaining consent, getting to know the participants and maintaining meaningful

dialogue throughout the interview and demonstrates how, as the researcher, I strived to achieve these. The form of analysis employed, was also chosen to optimise the chances of capturing the nuances and depth of interviews with the men.

The chapter concludes that additional time, careful preparatory contact, carefully constructed language and use of various means of accessible information are required when interviewing this population. This goes beyond the usual requirements of interviewing non-disabled participants. The following chapters present the main findings elicited from the analysis of men's accounts.

Chapter Six

How men with learning disabilities perceive and experience the impact of disability on their health

Introduction

This chapter explores how men with learning disabilities perceive and experience the impact of disability on their health. It examines the extent to which they are grappling with the adverse effects of disability and impairments on health, not only in relation to formal healthcare, but in relation to social lives as well. In doing so, it also takes account of the physical and psychological impairments they are facing, that are associated with learning disability. The chapter demonstrates that three critical dimensions to how the men experienced and understood the impact of disability on their health emerged from their accounts and these in turn form the main sections of the chapter. The first section echoes existing research (Lantman-de Valk, 2005; Emerson and Baines, 2010), which demonstrates that people with learning disabilities experience physical impairment in the form of more significant health conditions compared with the general population. However, the section also provides new insights into men's awareness of their health problems, and capacity for health promoting behaviour. The second section focuses on the significance of primary and secondary health care interventions. This demonstrates, in contrast to the problematic situation highlighted in some existing literature (Mencap, 2007a; Michael, 2008), that a number of the men reported positive relationships with General Practitioners (GP). The third section moves beyond health care

and focuses on the men's experiences of disability in the wider community and their implications for their health. Firstly, it examines their accounts of victimisation, specifically aimed at them as people with learning disabilities (Stephenson, 2009) and reveals its negative impact on their psychological and physical well being. Secondly, it explores the men's perceptions and experiences of friendships and social activities and their significance for their health. The findings echo existing research, which highlights disabilist constraints on friendship, for example limited opportunities to develop friendship groups, other than with people with learning disabilities (Cambridge and Forrester-Jones, 2003). However, the men's own accounts bring out that they had a clear perception of the value of friendship and the capacity for maintaining meaningful, confiding and reciprocal relationships over a period of time, and awareness of the benefits for psychological well-being.

Health profile and health promoting behaviour

Physical and psychological impairments

As previously noted in chapter two, existing research highlights the higher prevalence of health conditions amongst people with learning disabilities compared to the general population (Cooper, 2004; Lantman-de Valk and Walsh, 2008). People with learning disabilities have a higher incidence of conditions such as coronary heart disease, hearing and sight difficulties, mobility issues, epilepsy and mental health difficulties, which are specifically associated with learning disability, and are referred to as primary conditions

(Mont, 2007). They also have a predisposition to certain conditions that may undermine health, such as poor dental health, obesity or constipation, referred to as secondary conditions (Lantman-de Valk and Walsh, 2008). However, there is limited literature exploring the extent to which people with learning disabilities take responsibility for their own health (Wullink et al, 2009) and what influences their awareness of physical and psychological impairments.

In this study, with the exception of only two men, the men had ongoing primary and secondary health conditions. In terms of primary conditions, two men suffered from depression, two men had anger management difficulties, another man had an anxiety related disorder and one man suffered from epilepsy, in addition to sensory difficulties, such as sight difficulties. In relation to secondary conditions, six of the men were overweight/obese and three of the other men had hypertension, as well as other men having more general health conditions, such as asthma and compacted ear wax (see table 2). However, very little evidence exists as to how aware people with learning disabilities are of such conditions (Lantman-de Valk, 2009).

Awareness and capacity to manage health

Feedback from men across the study showed that they were aware of their health conditions. All the men were asked to rate their own health, identifying it as excellent, good, fair or poor (see table 3). Seven out of the

Table 2 Health conditions of participants

Participant	Primary Health Conditions	Secondary Health Conditions	General Health Conditions
Alan		Overweight	
Brian	Cerebral palsy	Hypertension	
Conner		Overweight	
Derek		Overweight	
Ewan	Anger management/ anxiety		
Fred	None reported	None reported	None reported
George	Epilepsy	Poor eyesight	
Harry	Depression		
Ivan			Ear wax (required syringing
Jack			Asthma
Kevin			Gout (prescribed pain relief)
Larry	Bouts of depression		
Mark	None reported	None reported	None reported
Norris	Regular dental care	Hypertension	
Oliver	Poor eye sight,		Asthmatic
Pete		Hypertension, hole in the heart (breathlessness)	
Rob	Anxiety/ self harming	Overweight	Asthmatic
Sam			Peptic Ulcers
Tom		Obesity	Chest pains
William		Obesity	Chest pains

Table 3 Participants Self Health Rating Value

Excellent (7/20)	Good (9/20)	Fair (3/20)	Poor (1/20)
Sam	Ewan	Alan	Tom
George	Fred	Brian	
Mark	Harry	Conner	
Oliver	Ivan		
Rob	Kevin		
William	Letwin		
Derek	Norris		
	Pete		
	Jack		

twenty men rated their health as excellent. Nine of the men rated their health as good, three as fair and one man as poor.

The following men rated their health as excellent, but they all still had significant health needs specifically associated with learning disability or more general health conditions of which they were aware. This may seem like a contradiction, but it has been shown that people with serious/long term health conditions can still define their health as excellent, if they have a sense of well-being, through their health conditions being well managed (Scambler and Higgs, 1999). The men concerned did demonstrate the capacity to manage such conditions, with prompting and support from health care professionals:

Derek: *I've a hole in my heart. ...I have to be careful not to rush around too much. I have to tell myself to slow it down as I could faint.*

George: *I still have epilepsy now. I've still got to keep taking my tablets. When I'm all giddy you know, I just go and lie down or take to my bed.*

Rob: I have a blue inhaler and a brown inhaler for my asthma. I ring up to see the receptionist [at his General Practitioner (GP)] cos she's got them all down on computer what I have and what I need to take.

Oliver: *The only thing I have now is asthma. It was bad in the past but it is controlled now. ...I just have to go for checkups every now and then.*

Jack: *I have good days and bad days with my health. I put it in my health book [communication book]. I have to go to the doctors, nurses, everything. I went the other day and they did see me last year but she didn't get one of my records out.*

George: *Sometimes I get angry; lose my temper and all things like that. They [the carers] say; "Just stay in your bedroom for a couple of hours and sleep it off". ...I do this just keeping my head down till I cool off.*

The ability to manage such conditions actively also demonstrates the men's capacity to act on guidance given to them, relating to their particular physical impairments.

The following accounts are from men who only rated their health as fair or poor. They perceived being overweight as contributing to their poor health, illustrating that they were making connections between health and weight. Alan was aware that he needed to eat more of the right food types and this was validated by the dietician:

Alan: *I'd probably say my health is fair. ..I don't eat the right foods. I went to see a dietician last year, to do with my weight.*

Although they were able to follow healthy eating/ lifestyle advice, these men appeared less inclined to do something about being overweight, without the prompting of others, or the advice from a health professional. They acknowledged they needed prompting to follow a healthier lifestyle:

Conner*: I am on a seafood diet; see food and eat it.*

Despite the jovial nature of Conner's comment, Conner was genuinely worried

about his weight but required moral support from his agency worker to go to his doctors initially:

> **Conner**: *She was someone there for moral support. To say, "Look Conner's worried about his weight."...The doctor said "Yes you are very overweight and you have to lose the weight". The doctor did put me on something called 'active for health' (free 12 months membership to the local gym).*

Tom also required a health professional, in this case his GP, to realise he was overweight:

> **Tom:** *I never used to be overweight but my GP's concerned about my weight.*

Alan is conscious about being overweight having been referred to a dietician and then having a follow up check at his GPs:

> **Alan:** *When I went to the doctor's for a check up they said I was a bit overweight.*
>
> **Researcher:** *So they referred you to the dietician*

Alan: *Yes.*

All the men who were overweight were being monitored due to their obesity levels reflecting the prevalence of obesity in the learning disabled population, compared with the general population (McGuire et al, 2007). The negative psychological impact associated with being obese is widely researched in the general population (Conradt et al, 2008). Whilst high levels of obesity in children and young people with learning disabilities have been reported (Rimmer et al, 2010), the impact of obesity on adults with learning disabilities, from their own perspective, is relatively unknown. The feedback in this study indicates that being overweight was a cause of anxiety for the men.

Taking on health promotion messages

In response to discrimination against this group of people (DRC, 2006; Michael, 2008) and the extent of health conditions within the learning disabled population as a whole, health practitioners working in the field of learning disability have developed specific health promotion activities (DH, 2007; Taggart et al, 2011). These have covered areas, such as healthy eating and smoking cessation programmes, and have been supported by policy initiatives emphasising health promotion (DH, 2001; 2005). However, whilst such approaches are assumed to be of benefit to this population, little

is known in terms of how people with learning disabilities perceive such approaches.

The following accounts confirm the benefit of aiming such activities at this particular group of men. It was clear that wider healthy eating/ lifestyle messages aimed at the learning disabled population in general (WHO, 2000), had been taken on board by this group of men. This highlights the benefit of pursuing a targeted i.e. anti-disabilist approach with them:

Derek*: I have to lose weight because my doctor says. I am on a little bit of a diet.*

William*: I keep on having cereals every morning. I keep on having sandwiches at lunch time and have tea at tea time. ...I keep on eating more fruit. I've not gone back onto vegetables yet, but I keep on drinking juice, 5 days a week.*

Rob*: As you can see I buy loads of fruit and that* [*pointing to bowl on his coffee table full of fruit*]. *I am trying to lose weight.*

It was not just men who lived independently who showed an awareness of

eating fruit and vegetables. Norris, who lived in supported living accommodation, was also aware of eating 'healthy food':

> **Norris**: *Oh yes I go with the carers to the supermarket once a fortnight. ...I know about vegetables and I eat them. I'm eating much more of them now.*

Other men also illustrated how they had become acutely aware of being overweight and how it could affect diet and lifestyle:

> **Derek:** *I go on the scales just to check my weight over. ...Oh yes and trying to eat healthy food.*

Similar to Derek, Tom is aware of trying to eat the right foods and recognises the link with this and being overweight:

> **Tom:** *I am trying to cut down. I don't like my fruit so much, but I have it with yoghurt. ...My brother in law was <u>nineteen</u> stone [suggesting this is very overweight].*

> **Researcher**: *And what happened to him?*

Tom: *Well he had two heart attacks.*

Some men demonstrated a more nuanced awareness of health-related behaviour. William reported drinking alcohol on a regular basis, but was also aware of the amount of units of alcohol present in a can of beer:

Researcher: So do you know anything about drinking and how it can affect your health?

William: *Well my dad has told me, because in one can [of beer], there are two units.*

Brian also demonstrated awareness of health and health-related behaviour related to drinking. However, he acknowledged that whilst he smoked and drank alcohol, he was still exposed to unhealthy care fumes:

Brian: *My mum makes sure I eat healthy meals. ...I have cabbage and cauliflower. Well the smoking and drinking's not healthy. But you cannot get away from the unhealthy fumes.*

Men's accounts here, usefully add to available evidence on how people with learning disabilities perceive and respond to health promotion approaches. The men were able to absorb and had the capacity to act on health promotion advice with particular reference to healthy eating. They also recognised their need for assistance from professionals or carers, to follow a healthier lifestyle. This, in turn demonstrates the benefit of pursuing anti-disabilist approaches to health promotion (Shakespeare, 2006), that target this particular group of men (DH, 2007).

Primary and secondary health care interventions

Monitoring and management of health conditions within primary care

Despite having significant health conditions and impairment related disorders (Kerr et al, 2005); existing research indicates that people with learning disabilities generally consult their GP less than the general population (Turk et al, 2010).

Health checks for people with learning disabilities within General Practice were introduced on an ad hoc basis in the late 1990s (Martin et al, 2005). As discussed in chapter two, existing evidence demonstrates that providing health checks to adults with learning disabilities in General Practice is an effective method to identify previously undetected primary and secondary health conditions (Baxter et al, 2006; Perry et al, 2009). Health checks for people with learning disabilities, have gained recent prominence within

primary health care, as GPs in England have been incentivised for carrying out health checks for this population (Chauan et al, 2010).

Research has indicated that health checks within primary care for this population could be enhanced if specific learning disability related health conditions were targeted, as opposed to indicators based on general health issues (Chauhan et al, 2010). The following extracts illustrate how the men themselves found it useful when their GP provided support to manage their individual learning disability associated health conditions, such as depression and anger management difficulties:

Harry: *I am on anti-depressants at the moment from my GP. ...I see him as and when I need to, so if I am bad I just make an appointment.*

George also pointed out that his GP suggested visiting him for a sedative to control his anger*:*

George: *I do get in bad moods and that. ...I get angry with people and [the GP] says; "Come to the doctor", to knock me out.*

Researcher: So is there no one else you can talk to about this?

George: *No, not really. He does tell me about it. He says; "Don't make a big deal of that again". He says; "Just go for a lie down and sleep it off".*

Similar to George, Rob's GP Practice is responsive to his incidents of self harming, which are related to stress:

Rob: *Yes, they are all nice up at the doctors. ... I went with my support worker up to the doctors to see one of the nurses. My support worker came with me and she said; "What's the matter?" I said "I'd like to see somebody, cos I keep having a go at my hand, hitting my head and that". She said; "Go and see somebody called Joan Smith [psychologist]".*

Pete had a hole in his heart, associated with learning disability and suffered from breathlessness and hypertension, and also found his GP helpful:

Pete: *Cos sometimes the blood pressure's still high. Yes, then when I go down to the doctors it goes down a little bit. He does it there and then, they check it three times. Depending how high it is, they'll increase like the dosage of the tablets.*

Pete, who was on regular medication, saw the importance of going to the doctor in advance to ensure he had enough medication for his holiday:

> *Pete: So I went down to the doctors and explained to him I was going away for Christmas and would it be possible to have 2 lots of tablets. The last thing I want is to run out of them.*

GPs have reported wanting to have an increased awareness of specific health conditions associated with this population, such as psychiatric conditions (Philips et al, 2004). The men's accounts endorse the value of these measures, indicating that this particular group of men valued being able to talk with their own GPs and primary health care team about such conditions. They also found the primary health care team helpful when managing such conditions.

GP's communication and understanding

A number of men reported having good experiences and relationships with their GP. All the following men had visited their GP in the last twelve months, either for a check up or in relation to a specific health condition and they felt their GP was good at explaining things to them:

> **Harry:** *My GP is an excellent GP. He's about 38 or 39. He's very modern in the way he does things. He has time to talk to you, not rush you through the door. ...And he understands me very easily.*

> **Brian:** *Any questions I don't understand he will just ask my mum. He talks to me first though.*

> **Pete:** *Yes the doctor I have got really understands. ...I got to know the nurse there as well, because I like to wind her up.*

Contrary to existing evidence (Michael, 2008), men's accounts of how they were listened to by their GPs, revealed how in these cases their GPs made every effort to communicate and ensure the men's cognitive impairments did not hinder understanding. In addition to feeling the GP listened to him, Norris also felt reassured by visiting his GP:

> **Norris:** *Yes, he's good at explaining things, the doctor is, yes. And when I come out of there, I'm more happy when I know what's what. I'm always happy when he's told me what the matter is.*

Health books/ passports have been developed for people with learning disabilities to help communicate personalised needs and health conditions with primary and secondary health care professionals (Kent, 2008). The following comment from Jack demonstrates how he feels the book helps the GP practice monitor his height and weight thereby aiding their understanding of his current state of health:

> **Jack:** *I can take my health book to the doctors I can and they know when I've been. Yes it does help. ...They check your height, your weight and check what you've been doing.*

These accounts show how, despite the men's cognitive impairments, the GPs in question appeared to take the necessary steps to understand and include the men in the consultation process, which reassured them. Their perception of being listened to and understood, equated to a more positive experience. This underlines how these men appreciate GPs and primary health care staff adopting responsive approaches that take account of their individual cognitive and physical requirements. This endorses the importance of how primary health care staff can ensure learning disability is not a barrier to providing effective primary health care for this group of men.

However, in contrast to the previous accounts, a number of the men did not have positive experiences when visiting their doctor. Their accounts also indicated that while there was no guarantee of men's responsiveness, it was important for GPs to be pro-active in instituting contact. In the case of Kevin, for example, he had not been to the doctors by himself for thirty years and only visited when he accompanied his wife during her appointments:

Kevin: *Well I only go up to the doctors when the wife goes. A couple of years ago I went up for a blood test with her, as the wife had it done as well.*

Researcher: Who asked you to have that done?

Kevin: *Well the wife had it done. ...And the nurse put the thing on around my arm. I thought my arm was going to blow off.*

Although he had gout, he had learned to live with the associated swelling and pain in his foot, stating the prescribed pain relief never helped:

Kevin: *There's no cure for it. They give you pain tablets. ...Well the tablets just make it worse, so I just let the swelling go down for three or four days. I've got to learn to live with it.*

The following extract from Ivan, also shows how he did not enjoy going to the doctors. He frequently suffered from impacted ear wax, a common complaint among people with learning disabilities (Martin et al, 2005). In this case, Ivan was reliant on his dad to clear the ear-wax for him as he felt the GP was not responsive:

Ivan: *They don't always listen to me no. My dad has to get the cotton buds and get the wax out most of the time. ...And I do make a load of it, but they [the doctor] don't realise that. They shove me out of the door some times as well they do.*

Letwin disliked taking medication and despite experiencing bouts of depression would not visit the GP for that condition. However, he would choose to attend when he felt he had general infections:

> **Letwin:** *I did go to the doctors a couple of months ago. ...I had some stuff to shift off my chest so I had an infection and was on a course of antibiotics.*

The following comment from Letwin illustrates how he felt strongly about not taking medication for his depression, which he recognised could be addictive. He was able to distinguish between medication types, acknowledging taking antibiotics was not addictive:

> **Letwin:** *I don't want to be on medication. ...If you're taking those things, once you are on them, then you can never fucking get off them.*

Whilst acknowledging some men were indifferent to their GPs, most men reported having positive relationships with their GP and members of the primary health care team. Existing research has highlighted that primary care for people with learning disabilities could be improved if health checks monitored specific health conditions associated with learning disability (Chauan et al, 2010). The accounts endorse this research, highlighting that the men benefited from GPs' responsive to their requirements as learning

disabled men and GPs being able to support and manage their specific health conditions.

Experiences of secondary care

As discussed in chapter two, reports have highlighted that people with learning disabilities can experience disabilist attitudes when receiving mainstream health care, in the acute care sector (Mencap, 2007a; DRC, 2008; Michael, 2008). A lack of concern and knowledge on behalf of health professionals working in hospitals have been reported as key factors explaining why people with learning disabilities have received poor care (Gibbs et al, 2008; JCHC, 2009). This is despite the General Medical Council (2011) provides specific guidelines on consent and reasonable adjustments required when doctors deal with adults with learning disabilities.

All the men were asked whether they had stayed in hospital recently. The majority of men were not able to recall experiences in detail, due to the length of time that had elapsed since their last stay. However, a number of men reported hospital stays that had taken place in the last two or three years and in general their comments were equivocal. Mark had very recently come out of hospital after having a kidney removed. When asked about his experiences of the doctors and nurses, he responded that the procedures were explained to him though he appeared to be unsure why he was having injections:

Mark: *They explained things to me to make sure I was alright. The doctor said, "Keep your vest on in bed, wrap yourself up warm". They gave me needles every night. That weren't very nice but they said I needed to have them.*

Jack was initially admitted to have his hernia removed. However, he ended up in intensive care following a negative reaction to the anaesthetic. The following account illustrates that while he may have felt the staff were very helpful, their lack of knowledge regarding his asthma had contributed to a serious problem:

Jack: *It was the anaesthetic, I couldn't breathe. ...They came quickly, four of them you know to sort me out.*

Researcher: But you felt the care was good?

Jack: *Oh yes it was brilliant. You know, the people were caring and loving. They were just doing what they are supposed to be doing.*

Jack's comments reflect a sense of relief but do not negate the fact that the staff did not consult his health book (Kent, 2008), which would have

identified he was asthmatic and possibly minimised the risk of a reaction to the anaesthetic and his resultant stay in intensive care.

Oliver was also ambivalent regarding his stay in hospital after rupturing his hernia and appeared to have to wait before his pain was properly managed:

Oliver: *Yes they were alright. They said; "The main priority is to get you into theatre as soon as possible". ...Yes and I woke up the next morning and I was in a lot of pain. I was screaming and asking for my mum. I was in a lot of pain.*

Researcher: And did they give you something for the pain*?*

Oliver: *Yes they gave me some tablets and water. ...They worked.*

Whilst these men appeared appreciative of the care they received in hospital, their experiences illustrate that care was less than responsive. In this way their accounts reflect other research identifying how this population receive sub standard care whilst in hospital (Gibbs et al, 2008; Abraham and White, 2009).

Victimisation and its impact on health

In addition to highlighting how the quality of healthcare and engagement with it had a significant impact on their health, men's accounts also revealed ways in which disabilist features of behaviour towards them in their local community, impacted on their physical and psychological wellbeing. This was apparent when men described examples of victimisation. As discussed in chapter two, while the context of care delivery has changed, with smaller living dwellings and more independent living options (Manthorpe et al, 2009), there continue to be incidences of bullying and hostile actions from neighbours and members of the public towards this group of people (DRC, 2006; Mencap, 2007b; Stephenson, 2009). A number of the men in this study, particularly those men living on their own or with a wife/partner, reported feelings of intimidation and incidences of victimisation with adverse consequences for their health.

Impact on physical safety

A number of accounts illustrate how the men experienced different forms of victimisation, which were a threat to their physical safety. This victimisation also forced men to move out of their accommodation:

Kevin: *The reason we moved from there is because we had trouble with the kids. They were shoving fireworks through the letterbox, stones and eggs at the doors and urinating up the front door.*

Rob: *Yes there were youths hanging out on our street and that is why we had to move. ...They were swearing at us and calling us names.*

The harassment was not only directed at the men but also members of their family:

Kevin: *I opened the front door once and it stunk. I had to get bleach and clear it away. ...And they kept calling my wife a witch.*

Rob: *Kicking the door in and calling us names and they tried to get my* daughter *out of bed.*

In Kevin's case, he had experienced abuse for a number of years before he was able to move. He had been fearful of reprisal and, therefore, never felt able to confront the youths. These circumstances also isolated him from his family:

Researcher: How long did you have to put up with this?

Kevin: *Oh about seven years. ...My relations would never come and*

visit me. I had to go to them. ...I would never go out to the youths,

because I don't want to get my bloody head kicked in.

Another man, Sam, also reported being pestered by youths when he first moved into his accommodation and like Kevin did not feel confident enough to complain:

Sam: *When I first moved here, youths used to pester me a lot. ...Knocking the door and asking for cigarettes.*

For Jack, whose appearance had certain features associated with learning disability, the harassment he experienced extended to when he went to the pub. He described a time he was sitting in the pub, minding his own business, when he was attacked:

Jack: *One person comes over causing trouble. I'm sitting there all night, minding my own business and they pulled my glasses off and attacked me.*

Ewan also reported feeling vulnerable following an attempted burglary:

> **Ewan:** *We've had problems from people down the park. ...They tried to break in here. ...And sometimes we have had kids coming around as well. ...The lady,* [*from the Housing Association*] *told us to phone the police.*

These accounts echo the recent and growing body of evidence pointing to higher incidences of disability hate crime aimed at the whole disabled population, inclusive of people with learning disabilities (Thomas, 2011).

Impact on psychological well-being:

The men's accounts illustrated their own sense of vulnerability. This was directly associated with incidences that occurred both near and away from their homes. Kevin, for instance continued to feel victimised and vulnerable despite moving home:

> **Kevin**: *I was talking to the bus driver and this bloke came up to me, he said; "You know me?" and I said; "I don't". He had a go at me. He then called me a paedophile and told my wife to 'f off' as well.*

> **Researcher:** Have you ever had other people being aggressive and intimidating to you like that?

Kevin: *Well just from kids where I live now. ...But I still get that same feeling; I am going to get hit by that bloke again. I never met the bloke, but I still get those feelings when I'm out that he's going to do it again.*

Kevin also felt vulnerable entering his home and carried a torch because he felt nervous, particularly as there was a lack of street lights near his home:

Kevin: *Because it is dark around here. I've told the council to put a light here [referring to his porch]. I think as I put the key in I am going to get a knife in my back. ...And my missus feels the same. She says: "I will go in first". And I say no; "I'll go in first, I have the torch".*

A number of the men highlighted how feelings of vulnerability and victimisation impacted negatively on their health. In particular, they reported their perceptions of the ways in which such incidences affected their sleep. For example, when Jack was asked about how he felt when youths jumped into his garden late at night, he responded:

Jack: *It affects your sleep and you need your sleep:*

Rob recalled how the victimisation he experienced at his previous flat affected him:

Rob: *Yes, I wasn't sleeping very well when all that was going o*n.

Pete also referred to his sleep being affected by his experiences of youths knocking the front door and driving a car close to the kitchen window of his current accommodation:

Pete: *It was just like I was not eating and losing sleep.*

Sleep deprivation is widely acknowledged as impacting on optimum health and affecting cognition (Jung et al, 2011). Thus, men illustrated the insidious way in which victimisation adversely affected their psychological as well as physical health. These accounts also confirm the men's own sense of vulnerability and the difficulty they had speaking out against the harassment experienced. Perpetrators of hate crime targeted against people with learning disabilities, reflecting ingrained negative attitudes towards people with disabilities, have been found to judge disabled people as worthless, and unreliable witnesses, and therefore easy targets for maltreatment (Balderston and Morgan, 2009). However, the men's accounts here show that given the opportunity to relate their own experiences and perceptions, the men in this study were able to articulate the specific impact on their health resulting from abuse. These included experiences of continued anxiety, even after moving home. In these ways, obtaining men's own perspective extends the reach of existing research where men with learning

disabilities have been victims of hate crime (Stephenson, 2009; Balderston and Morgan, 2009).

Social Networks and Friendships

The chapter now moves on to discuss social networks and friendships and how these in turn have an impact on the health of the men. The need to develop and maintain relationships with others is of fundamental importance to psychological well being (Lippold and Burns, 2009) and has also been found to be associated with improved chances of physical health (Wilkinson and Pickett, 2009). Existing evidence suggests that people with learning disabilities generally have reduced social networks and fewer close relationships than the non-disabled population (Lippold and Burns, 2009). This lack of social support can leave people with learning disabilities vulnerable to social isolation and mental health difficulties (Cooper et al, 2007). In doing so it provides a further dimension to how disability can impact on the health of these men.

Social isolation

In the UK, policy has continued to emphasise the importance of people with learning disabilities leading independent lives (DH, 2001; National Assembly for Wales Learning Disability Advisory Group, 2001; Scottish Executive, 2002). However, this has not always taken account of the potential negative impact on psychological well being, if individuals feel isolated and lonely. All

the men were asked about 'going out' and who they socialised with. Some of the men, who lived independently, did highlight experiences of loneliness. One man was able to explain how he found it difficult meeting girls, which he put down to being short and young looking:

Harry: *In relation to relationships that's also hard to get them. I mean it's hard for me to get by because I don't really always look my age so I'm not taken seriously. From the woman's point of view, it's almost like they would see in a mother, son way.*

Researcher: So have you had many relationships with women?

Harry: *It is difficult to find them. To make them work. I mean ideally I'd like to find a long term one, but I don't think I'm ever going to find it. ...Wherever I go, I feel I'm the one that's out of place. I'm not tall enough to be taken seriously. So you know, I mean, the only reason I've got moustaches is so I can get into a bar.*

Harry is aware that he is different and his comments reflect a sense of loneliness and despondency in terms of believing he will never have a meaningful relationship. Harry's situation is compounded by both bouts of depression and his perception of his social deficiencies, associated with being a learning disabled man.

Brian used to live independently and had since moved back to live with his mum. He also described a sense of loneliness associated with living on his own:

Brian: *I just had no one to talk to. ...It is better now I am living back with my mum.*

Brian's comment echoes seminal work by Atkinson and Williams (1987), which revealed people with learning disabilities describe their quality of life in terms of the people they shared a house with and relationships with members of their family. Brian values the close relationship he has with his mum, compared to feelings of isolation experienced when living on his own.

Friendships within the learning disability community

Previous research has also indicated that where people with learning disabilities do have friends, the pool of individuals from which they have to select their companions is limited, for example, typically confined to other people with learning disabilities and service providers with whom they have most day to day contact (Pockney, 2006). However this was not considered problematic by the following men interviewed here. They were content to have friendships and support from other people with learning disabilities and carers. Derek, for example, perceived the people he saw on a regular basis

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as his friends, such as those with learning disabilities he knew from work and his Swimming Club:

Researcher: So do you have any other friends that are not in your family?

Derek: *No. ...I do have friends at the swimming club I see every Sunday. ...I have my old school pal John [friend from special school], I see at work.*

Researcher: But do you see him outside of work?

Derek: *No.*

Tom and William shared a house and had known each other for many years. Although much of their socialising was done together they did claim to have other friends:

Tom: *Well I go back to Grove Park Community Centre to my friends twice a year. I see them once or twice a year, at Christmas but not all the time.*

When asked if he had friends other than his family, he replied:

Tom: *I do have other members of my family I see. ...I have my cousins, my stepbrother.*

When asked the same question William replied:

William*: No I don't, but I do have my Aunty, my mum's sister.*

Similar to the previous accounts, Norris and Mark's socialising was organised for them and centred on activities with other people with learning disabilities. They also found it was the staff at the home they would talk to if they had a problem.

Mark: *Yes it is the staff I would talk to if I had a problem.*

Researcher: *You wouldn't talk to your friends.*

Mark: *No. I would talk to the staff.*

Norris would also rely on carers where he lived:

> **Norris***: If I get any problems I go and see one of the carers here. Either see Julie or I can go and see Tracey, whoever is in charge. I go up the office and see them in the office. ...They're people I can talk to quite a bit here.*

In terms of specific social activities, Norris and Mark lived with other men with learning disabilities and they would all go to see the local football team together or go shopping, accompanied by a staff member.

> **Norris:** *I go down the matches every weekend, cos I have a season ticket that my brother paid for. ...I go down with my carer and three of the lads from here.*

> **Mark:** *I go into town shopping. When the staff come down we just walk into town together about 9 o'clock.*

It was also the case for George, whose socialising centred on doing activities with the person he lived with who had learning disabilities:

Researcher: So what types of activities do you do with Geoff?

George: *Well he helped me unpack all my boxes in my room. ...And sometimes we go fishing together. ...He does like it but sometimes he gets a bit bored with it though.*

Whilst the lives of many people with learning disabilities have been shown as not providing them with opportunities to form friendships or networks outside of their family, home or school (Cambridge and Forrester-Jones, 2003), these preceding accounts illustrate how a group of men could be satisfied with this situation. This resonates with other research highlighting how people with learning disabilities reported being most satisfied with their relationships, when a greater proportion of those relationships were with other learning disabled people (Gregory et al, 2001).

Pro-active in extending their social circle

As previously discussed, it is generally assumed that people with learning disabilities' have somewhat constrained social networks (Johnson et al, 2010). However, the following men described being pro-active in undertaking various activities to extend their friendship circle. In the case of Letwin, he would frequent regular séances:

Letwin: *I've been going to this thing called; 'Whispering Friends'. ...We try to communicate with spirits. ...I saw the flyer in the local pub. ...I feel I have got closer to people.*

Harry: *I go to the Model Railway Club on a Tuesday and Thursday. I got into model railways when I was a kid.*

Harry perceived the other men at the Model Railway Club to be part of his social network. However, he did not spend time with any of the men other than during the Tuesday or Thursday club night:

Harry: *Yes I know all the guys there. Most of them are older than me, in their 40s, 50s or retired, but they're a great bunch of guys. ...We've massive lay outs and some nights we start at seven and don't finish to ten. It's quite a good night.*

Researcher: So do you go out with these guys any other time?

Harry: *No, not really, we are planning a Christmas party there this year. Well that's what they have told me.*

Studies of people with learning disabilities moving out of institutions have shown they do not have contact with those remaining in the institution (McConkey et al, 2003), and moving out of institutions can lead to isolation and loneliness (Johnson et al, 2010). The account from Sam, a man who used to reside in an institution still reflects a degree of social isolation, but even in this situation he was actively seeking new opportunities to extend his social sphere and have an experience of 'having company' that he found rewarding and congenial. He would, for example, often spend his time at a local university campus because he enjoyed the social environment:

Sam: *Well, it's a good atmosphere there. When people say it is only for the university staff and students, you can still go in there and enjoy the atmosphere, can't you?*

When asked what Sam did when he was there, he replied:

Sam: *I sit down and have a soup. …Yes I talk to people in the cafe bit. ...It is the atmosphere I like about it. They have music in there and a bit of dancing for the students.*

Pursuing friendships with non-disabled and disabled men

All the men were asked what sorts of activities characterised their time with their friends. This revealed that some of the men did different activities with both non- disabled and disabled people. For example, Alan discussed meeting up with non-disabled men in the city centre:

Alan: *We normally meet up once a fortnight in town and go for a couple of drinks. ...I get on the bus to meet them.*

Alan would also attend a drop in centre for people with learning disabilities, where he played pool and then went on with these friends to a pool bar.

Alan: *I go to play pool with the church end lot. ...Then we go over to a local pool hall.*

Conner also visited the same pool hall, but with his non-disabled friend.

Conner: *We go to Jimmy's. I don't play very well but my mate, he's been playing there since the Romans. He's pretty good.*

Researcher: Are there other people that you socialise with?

Conner: *There is this Trackside place; they provide sort of social activities over by the river. ...They [the people there] have disabilities as well. It happens every other month.*

Capacity for confiding friendships/relationships

The following accounts demonstrate the ability of the men to form, maintain and understand the benefit of meaningful friendships and relationships. In doing so, they also illustrate how such friendships could be informed by the notion of reciprocity or 'exchange'. This has been shown to be very important within friendship interactions generally, as compared to other social relationships. Friends are reported to trade information, support and sociability (Jamieson, 1998). Oliver, the youngest man interviewed, was able to recognise the importance of having friendships for psychological wellbeing:

Oliver: *Yes, it is good. It gets me out the house and that and gets me to feel myself again. ...I have other mates we go for a few drinks.*

Oliver had just fallen out with his close friend over a girl and was trying to repair the relationship:

Oliver: *I did have a close friend. I used to hang round with my mate but we're no longer mates any more. Cos what I did, I was drunk on*

Saturday night and I asked his girlfriend out. ...But I wish I hadn't cos I have lost a mate in the process.

Researcher: So the friendship must mean quite a lot to you?

Oliver: *Yes, quite a lot. But we're talking now we're talking about what happened.*

As a homosexual man, Letwin travelled to another city to do his socialising with other men. When asked about his friends and the people he met, he responded:

Letwin: *I am not very good at socialising with other people with learning disabilities. I only get acquainted with people I feel comfortable with. ...I try and get to this club once a month. ...Its gay men having a good time with each other.*

Letwin was also able to perceive the psychological benefit of having these friends:

Letwin*: It sort of boosts me up, makes me feel good.*

Pete: *I've got friends as well. I just go around and call on them. ...Just normal people. I got a friend, who lives in the block [same block of flats], a friend with a computer.*

Despite having a support worker who visited him three times week, it was his friend Michael who Pete turned to and relied on:

Pete: *It's mostly Michael. ...I'd be a bit stuck without him, yes.*

Not having a computer or access to the internet, Pete described how Michael helped him when he was considering moving flats:

Pete*: First you got to register on line, at one time, when you wanted to move. ...My friend phoned up for me. ...Then he phoned them up and says how I go about moving and that. It's like less paperwork doing it online and at the time, before my friend helped me, it was all this paperwork.*

Sam went to car boot sales and helped to clear away at the end. He met his friend there:

> **Sam***: I've known him for ten years. ...I got to know him when I went to the car boot sales and we used to go for dinner at the Club. ...He's a good friend to me.*

Unfortunately his friend was in hospital at the time of interviewing Sam. This was clearly upsetting for Sam, but he managed to visit him in hospital on a regular basis:

> **Sam:** *He's got the chance to live for another 2-3 years. I have to see him every day.*

Existing research suggests that people with learning disabilities can overestimate the existence of friendships, experiencing relatively superficial relationships more usually associated with acquaintanceship, as friendship (Lunsky, 2006). Whilst acknowledging that these men have only less severe learning disabilities, the accounts from Sam, Pete and Conner, in particular, dispute this research, demonstrating the ability to form reciprocal friendships and sustain friendships for themselves, over a prolonged period of time.

It was also the case that some men had girlfriends. As discussed in chapter one, exploring the nature of the men's sexual relationships was beyond the scope of this study. However, their relationships with the opposite or same sex were considered, in terms of the extent to which they offered

opportunities for close, confiding relationships, which have been found to be associated with better chances of psychological and physical health (Hardy, 2002). Mark and Norris both had girlfriends who they saw on a regular basis. Both of their girlfriends had learning disabilities and lived in another supported home in another area of the city. Both men made a point of saying they could visit their girlfriends when they liked, therefore, perceiving that they had a degree of freedom over their relationships:

> **Norris:** *There's another home up there. I go up and see my girlfriend up there. I keep in touch with her all the time.*

> **Mark:** *I can go and see my girlfriend any time I want; "Come in I'm not going to stop you", says the woman in charge of the home. "You can come in anytime you like", nobody else, only me.*

Norris is able to illustrate what the relationship with his girlfriend means to him:

> **Norris***: I can talk to her about anything, she's a nice person. She makes me coffee and that. Makes me welcome, she does, she's a nice girl.*

Mark also described how frequently he sees his girlfriend and how they spent their time:

Mark: *I always phone her up at weekends. I saw her last weekend on Valentine's Day. She cooked me a meal and got me a card. And I got her a card. We keep giving presents that way, we do.*

Researcher: And where did you have the meal?

Mark: *At the home where her carers are. ...I go there regular.*

Like Norris, Mark felt it was important having a girlfriend as it was a person he could talk to about anything:

Mark: *Yes, it is important cos I like Sharon, she's alright. ...We get on well together. I could talk to Sharon or could talk to one of their carers about different things.*

Furthermore, Mark did not seem aware or bothered by spending time with his girlfriend in the company of carers. His account illustrates the importance of spending time with his girlfriend even if the staff were present during their time together*:*

Mark*: I don't go out on my own anywhere. I go with my girlfriend to the pub for a meal. ...We go out with her and the carers.*

Concerning the significance of the role of friendship and social networks for health, there were instances of loneliness associated with learning disability. For several of the men, friendships were also centred on family, carers or with other people with learning disabilities. However, in various ways, these findings dispute other studies. Contrary to existing research, several of the men were able to move beyond 'facades of friendship' (Lunsky, 2006), maintaining reciprocal friendships and relationships over a period of time. These also provided examples of confiding relationships, and were valued as such by the men. Departing from the picture presented in Johnson et al's account (2010) that the friendships and networks of this group of people are usually structured on somewhat segregated existences and family carers, a number of the men were able to engage in friendships, both with people with and without learning disabilities. Furthermore, they exercised a degree of autonomy over their social lives. Overall, echoing more general research identifying the benefit of friendships to health (Christiakas and Fowler, 2010), the men were also able to articulate the importance of friendships to their psychological well being.

Conclusion

This chapter has examined how men with learning disabilities perceive and experience disability and how it can impact on their health. It has shown that

a significant number of men experienced impairment in the form of specific health conditions associated with learning disability, thus confirming existing research. However, the findings here extended current research with evidence of how the men demonstrated awareness of such health conditions and the capacity to manage them, with support from health professionals. Significantly, the men felt their relationship with their GP was enhanced when their intellectual impairment was not seen as a barrier to understanding, and the GP was prepared to advise on specific health conditions. Although the literature is limited, GPs in general could benefit from following educational materials provided by the Royal College of General Practitioners (2010), to enhance their knowledge of specific learning disability related conditions, thereby taking an anti-disabilist approach. However, the adoption of similar anti-discriminatory practices was not as evident in men's accounts of secondary care. These findings contribute to confirming the importance of anti-disabilist initiatives in primary and secondary care. Notably, as an encouragement to health professionals to undertake health promotion and health checks in primary care, the men's accounts illustrate a substantial level of responsiveness on their part, when these are carried out.

The men's accounts also added to understanding of the health consequences of disability hate crime. They showed that providing the opportunity for men with learning disabilities themselves to describe their experiences and perceptions brought out how disabilist victimisation

threatened both physical and psychological well-being, and could have insidious long term effects.

Drawing on the commentaries from the men, reflected existing research in that their friendships and social networks largely took place within the learning disabled community. However, apart from a couple of exceptional cases, where men felt isolated and lonely, the majority of men were content with their existing social network and friendships. Hearing from the men also extended existing research, by revealing how men were able to undertake different types of social activities on their own initiative, with disabled non-disabled men as well as disabled men. Finally, in contrast to existing research, the men's accounts also suggested that they had the ability to form and maintain meaningful friendships and relationships and demonstrated a lucid understanding of the positive impact such friendship can have on psychological health. This also indicates that existing studies may have failed to do justice to men's capacity to form meaningful and prolonged friendships and relationships, a key resource for health.

Overall, by drawing on men's own accounts, the chapter provides a fuller, more nuanced understanding of how men with learning disabilities are grappling with the impact on their health of different dimensions to disability, and impairment. The next chapter will report on another key dimension affecting the health of this group of men; how men experience and perceive the impact of relative poverty on health.

Chapter Seven

How men with learning disabilities perceive and experience the impact of relative poverty on their health

Introduction

This chapter explores how these men perceived and experienced the impact of relative poverty on their health. Income, employment and the neighbourhoods in which they lived, all emerged as playing a significant part in this and therefore form the focus of the three main sections of the chapter. The first section echoes existing research relating to people with learning disabilities (Wistow and Schneider, 2003), in that all the men were on low levels of income. It goes on to compare and contrast the experience and perceptions of men receiving support from family and paid carers in terms of extra income and/or help with managing their income and those living independently. It demonstrates that the former appeared content with apparently very limited amounts of disposable income, but argues that this situation should not simply be assumed to be unproblematic for health and well being. In contrast, men who were living independently on low incomes had to develop a range of strategies to make ends meet. These men reported shortages of necessities and were also aware of how being forced to 'go without' had a negative effect on their psychological well-being.

The second section of the chapter examines the men's varied perceptions and experiences in relation to employment. Some men were unemployed,

but appeared content to be without work. Some felt their preferred choices of employment were constrained by their carers. Men also reported how their physical and psychological conditions could impact on their employment situation. In addition, employment did not emerge as a straightforward route to greater physical and psychological well-being, as promoted by current policy (DH, 2009). Instead the findings showed that jobs were mostly part time or voluntary, with low status and low income, a situation which a number of the men found demoralising and frustrating and poorly paid. In addition, in most cases, whether men were in work or not, welfare benefits underwrote men's income.

The final section of the chapter examines a further dimension to relative poverty experienced by most of the sample, namely living in disadvantaged neighbourhoods and its impact on health. In presenting this evidence, the chapter goes beyond existing research, which has identified that people with less severe learning disabilities are likely to be living in such neighbourhoods, but which has not explored people's own perceptions of this. This section shows that this group of men often had a sharp appreciation of the threats to physical safety and psychological well being associated with living in a disadvantaged neighbourhood.

Income

All of the men were asked how they were managing financially. Two men,

who reported they were doing well, appeared to be in exceptional circumstances in that they were in receipt of benefits and also had an income from their families:

Sam: *Quite well…I get a few papers and magazines and I buy food and save the money for the next day and then the next day. If I want a bit more money out, I can have a bit more money out.*

Conner: *I'm doing alright. I'm managing to save fifty pounds into my [building society] account. Cos I don't have to pay council tax and my council tax was about eighty pounds, so I can save that. …I've got quite a few accounts actually, but the two I've got, I've got one for my bills. …One where my rent gets paid. Dad pays into that. I think my working persons' tax credit gets paid into that as well. The other account is for what I could spend on you know, what I want.*

Sam had access to a trust fund left to him by his deceased parents, while Conner had his private rent of £350 per month paid by his father. Conner also demonstrated a good appreciation of his benefit entitlements and how his money was organised. Both responded positively when asked about their financial circumstances and both reported the opportunity to save money each month.

Support with money and management

Promoting independence and enabling people with learning disabilities to make everyday choices has been an influential policy driver for the last four decades (DHSS, 1971; DH, 2001; 2008a). The notion that people with learning disabilities both have and want financial independence is an important aspect of this shift in policy. However, the accounts of several of the men who lived with their parents, demonstrated how these men did not desire to have financial independence. It was also the case that those men who lived with their parents were far less likely to report concerns when asked about their current financial situation. For example, both of the men in the following two extracts received 'pocket money' from their parents:

Brian: *My mum looks after all my money, I ain't got a clue.*

Ivan*: My dad always gives me money. I am ok. ...Every week on a Saturday I get ten pounds for a drink.*

Another of the men in this group, Derek, used his pocket money to buy his father a drink after church on a Sunday. He expressed no desire to have more control over his finances:

Derek*: My dad goes down the pub after mass and I go with him. I buy*

him a drink. ...I have got my own money. My mum puts it in a purse for

me.

Researcher: Would you like to be in control of your money?

Derek: *No.*

Men living in supported living accommodation also demonstrated a similar reliance on others in terms of managing their financial circumstances. For instance, when asked how they would like to spend their money, their responses showed how staff members were central to their financial decision making, though these men appeared to have more control concerning the amounts of money and range of goods and services involved:

Norris: *They [the staff] ask "You want so much out from the cash point for the weekend?" They give me a bit for the weekend they do. ...If you want things for the house, we go to the bank and we draw down and buy things for the house, like pictures and things like that you know. Picture frames and things like that. I got that up there [pointing to a picture on the bedroom wall].*

Mark: *Yes I get twenty pounds per week. ...It helps me, yes. Buy things*

that I like when I want to buy something. I buy things for my bedroom and new shoes for my holiday. We pay rent and the office see to all that. I've got a lap top. I have got everything now.

Another of this group of men expressed a similar lack of material or financial concerns. His main bills were sorted out for him and he tended to concentrate on relatively small items of expenditure, as was the case with the two previous examples:

George: *I just buy things when I want with it you know. ...Cakes, Bakewell tarts. No, I am just fine for money, just fine.*

Researcher: Is there anything you would like to buy?

George: *I do buy flowers for the kitchen you know.*

It was also the case that family members would take care of managing the finances of certain men, providing them with set amounts of money to buy food and so forth for themselves. This family management appeared to 'cushion' the men from financial concerns and they were seemingly content with these arrangements. When asked how they felt they were coping financially, they responded positively:

William: *It's excellent, sometimes when I go to Morrisons, I keep on getting money out. I have fifty pounds a week to do your shopping and for toiletries. ...I pay that into my Mum's account and it pays the whole bills off.*

Tom: *Normally I would spend about £45. That's what my Mum prefers me to do. I have benefits but I am not really sure.*

Fred: *My sister does that for me…Yes she goes shopping every Saturday once a week. …Pays all my bills. …I get a fiver sometimes for pocket money.*

Whilst these men had limited comprehension of their benefit entitlement, they appeared positive about their low income status. However, although their situation may appear unproblematic, Brown (2010) has demonstrated that this group of people are vulnerable to different forms of abuse. Recent studies in this area have highlighted that sixty percent of adults with learning disabilities have experienced some form of abuse, including financial abuse (Ann Craft Trust, 2009). The financial dependence of adults with learning disabilities makes it difficult for them to have the choice to move away from care that may be below standard and goes unchecked by authorities. The way in which benefit payments are received by carers, can also leave adults

with learning disabilities with little control over what the payments are spent on, potentially depriving them of items they need (Brown, 2010).

While all of the men mentioned in this section received relatively small amounts of money, they appeared to be unaware that they had a low income or the disadvantages associated with it. In contrast, one of the men who lived at home did have some perception of financial difficulties facing his family. In the following extract, Oliver, who lived with his mother and sister, recognised that finances were constrained within the home:

Oliver: *Yes, just my mum can't afford much ... Which she can't. Cos I mean she is struggling. She's doing so much overtime. She's getting up early. She's going to work at 4.00 in the morning. ...Yes it is a very hard process. ...But she can't do too much overtime cos she's got me, my sister and the dog to look after.*

Although this study is not designed to address issues relevant to the wider disabled population, Oliver's comment reflects the financial difficulties facing many families with disabled members on lower income and the reduced household income that results from caring for a disabled member (Graham, 2002).

Living independently: Awareness of low income

The men living independently were aware of having to 'get by' on a reduced income. The monthly income of the eleven men who lived independently varied between £390 and £900, inclusive of benefit entitlements. Compared to national average income, even men in the study at the top of this income range would fall into the lowest quintile of disposable income (Marmot, 2010). As discussed in chapter three, these socio-economic circumstances are consistently associated with poorer chances of health.

A number of the men who lived independently were aware they also required help with financial management, but as a result of having to manage on a low income also feared getting into debt:

Pete: *[Support worker] helps me with all the bills I've got to pay out. He writes it down on a piece of paper or I will get in a muddle and then they get the bailiffs out and that.*

The following comments by Kevin and Harry illustrates the negative psychological impact associated with being reliant on others for financial support, when that support is inadequate. They then had to live with the consequences, which in Kevin's case was the fear of being evicted:

Kevin: *A lot of debt. Well, when we had that come in, like a gas bill. I said, 'Sort it out for me and let me know next week'. Next week come, I said, 'Did you sort that?'…'Oh yes', she [support worker] said yes, but she didn't. She kept letting the bills go higher and higher. She got us into bloody debt. About two thousand pounds in debt. If it wasn't for that new support worker, we'd have been ... we'd probably have been evicted because we had the bailiffs here and all this.*

Harry: *When I moved into here, they [family] didn't take the loan off my hands when they should have done. And then I ended up being three and a half thousand pounds in debt. And I had to take a loan out to cover that to pay all my bills to put me up right. So my loan was taken out to pay my bills and I had nothing when I moved in, except what was in the bedroom, the bedroom furniture.*

Another of the men also required financial assistance and had to take out loans to get basic items for his flat. He expressed concerns about getting into debt and as a result kept proof that items had been paid to demonstrate they had been paid:

Rob: *My sister and my niece sorted all that out for us. Cos she put it all paper bills out again and that ... so doing alright with the electric and water. And I've got all the receipts as well for them. I keep all the receipts*

in case anybody comes, like the electric man, the water man and all that

lot. ...Well, I've got fridge and cooker. …Yes, they're all from Bright

House [Electrical Appliance Loan Company] and I pay them as well, so

that is another bill as well.

Another of the men, Harry, remembered being in debt previously and
wanted to stay in control of his money:

Harry: *I mean at the moment I'm more really interested in paying off*

what I owe and then getting my accounts back to the black as it was

before it happened.

Living independently: budgeting and 'going without'

The chapter now moves on to the accounts of those men living
independently. When asked how they felt they were coping financially it was
clear that money was constrained and that they had to budget carefully:

Harry: *I have a set budget of seventy pounds. My budget is to hit under*

that. So what I tend to do is I buy shopping for a week and then ...

whatever is left in the fridge makes up whatever meals is left. So when

the fridge is empty then I go shopping. I don't let the fridge get too

cluttered. I tend to be a bit of a penny pincher, I go wherever I can to get

the cheapest wherever it is. I never buy the best of the best. I always buy

the basic food range, which is very good food and is no more expensive

than Tesco in price.

Often, it was as the interviews progressed that the scale of their relative

poverty became apparent. Rob, for example, was initially reasonably

positive regarding his financial position:

Rob: *I have £60 per week on food for me Margaret and June and*

whatever's left I put in the pot and that.

Researcher: So do you think you have enough money each week?

Rob: *No, well just about alright*

However, having claimed that his financial situation was '*about alright',* it

became apparent that he and his family were not able to buy a range of

goods which other people may take for granted:

Rob: *Some new clothes and that would be good ... we just have them on*

birthdays and that. Well me and the girlfriend get some new clothes on

birthdays and my daughter gets new clothes on her birthday ... Cushions

and duvets, yes cushions they are really expensive.

This lack of basic items was apparent across a number of these men's accounts:

> **Jack:** *I'd like a new tele, maybe some blinds for my room and quilt on the bed. You just have to save. I have to be careful you know. I have to pay my bus fare in the morning, swimming at night, have a drink, sometimes just one or nothing at all.*

> **Kevin***: I wish I had money to have a pint, a packet of fags, you know, or whatever.*

This was also evident in the account of one of the men who lived independently, who appeared to struggle financially on a daily basis and who reported having to borrow money from people around him, such as friends:

Pete: *I'd like more food and that ... cos I keep borrowing off a person. That's what it is. It means I have to pay it back, no matter how much I have ... and then after paying the bills out it leaves me short.*

It appeared that Pete was forced to borrow money on a fairly regular basis:

Pete: *Then like all the bills like TV and water and that. I can cope but just need care worker and that, he helps me. If I haven't got enough money left my friend lends me some until I get paid. This is when he gets paid, he will lend me some and when I get paid I pay him back.*

His account also reveals how he was forced to buy reduced price food and had to consciously target food close to its sell by date:

Pete: *Say if I went down to Iceland today. …Whatever's going, it would be like reduced … have like today's date on it ... things on offer, like cheap, just coming out of date order. The dates just coming up. If I've got like five pounds or a tenner left over one week, probably go and buy a small chicken and that.*

He also admitted that he went without food and tended to buy relatively cheap but 'filling' foods:

Pete: *Sometimes I don't eat in the day time. It's mostly like I eat at night time. ...I don't have breakfast. …I do like chips and that. I just get them from Iceland and that, or if I've got any potatoes left, I just use them, especially like if I'm in town, going to the Pound shop, and get like, loads of big packs of crisps, that's all I eat.*

In addition, Pete also performed errands for his neighbour, for example, taking her dogs for a walk, in return for a cooked meal:

Pete: S*he's got four Yorkies [Yorkshire Terriers] and I just turn up and take them out and she gives me a hot meal and that*.

Finally, the following comment further illustrates how his lack of income and inability to buy food was a key feature of his relative poverty:

Researcher: So if you had money in your pocket at the end of the month. What would you like to buy?

Pete: *Like more food and that.*

Pete's account reveals how he developed strategies to enable him to pay his bills and made potentially health damaging choices, such as going without food, because of his limited income. A number of the other men living independently recognised that they too had little disposable income. When asked what money they were left with at the end of the week, the responses indicated the men had a perception of financial hardship:

Alan: *I feel a bit 'skint' sometimes, yes*

Harry*: What's left in my pocket. Nothing's in my pocket.*

Rob: *Sometimes I feel a bit skint on a Sunday*

This is perhaps best illustrated when Kevin was asked if there was anything he felt he could not afford to buy, he responded:

Kevin*: I feel like a lot of things, Martin. I had a bike, but that got bloody nicked. I was paying £10 a week to buy it out of my dole money*

Evidence from the wider literature on relative poverty has shown how people in poorer social economic positions are often forced to go without food (Graham and McDermot, 2005). However, to date, there has been no reference in this literature in relation to how men with learning disabilities cope with living in relative poverty.

The psychosocial impact of living on a low income

A number of the men who lived independently also acknowledged the negative impact on their health, in terms of the stress and worry, which they

associated with financial management and getting into debt. The combination of reliance on others for financial support and a fear of debt were acknowledged as having an adverse effect on their psychological well being:

Kevin: *It was [stressful]. Cos it was pay this, pay that. ... If we didn't pay ... we would have been out on the bloody street. ...You feel low with no money in your pocket.*

Harry: *I am wasted trying to sort it all out myself. ...They have told me I suffer with depression. He's [GP] had me on meds for that and I've been in and out of Occupational Health counselling.*

As noted earlier, the notion that people with learning disabilities need to gain greater control of their own finances has been a central policy issue; which is seen as a key way to promote independence for this group of people (DH, 2008a). However, these men reveal that control may not be something that all men desire. Moreover, whilst these men were managing their income independently, their incomes were less than adequate and so the notion of 'control' may well be misleading. In other words, some of these men may have had greater financial 'independence', but their low incomes meant they had to cope with the impact of relative poverty, which had adverse consequences for their health. The next section moves on to explore the

men's perceptions and experiences of employment and the associated impact on health.

Employment

For many people with learning disabilities, obtaining paid employment and maintaining employment has been found to be an enormous challenge (Broad, 2007). Despite a recent strategy to promote more meaningful employment options for people with learning disabilities (DH, 2009), being without work is still an integral part of the lives of many people with learning disabilities (Maguire, 2009). The evidence suggests that less than twenty percent of people with learning disabilities are in some kind of paid employment (Emerson, 2005). As discussed in chapter two, the discriminatory attitudes of others view people with learning disabilities to have a reduced capacity to work, due to communication and physical health difficulties (McConkey and Mezza, 2001). This highlights how disability combine with the reduced employment opportunities maintaining men with learning disabilities' reduced socio-economic position.

Experiences and perceptions of being without work

All of the men in this study were asked about their experiences of employment. In the case of one man, Pete, the state of his physical health had precluded him from employment. Pete had been unable to work for ten

years due to a hole in the heart and hypertension. He perceived these conditions impacting on his work opportunities:

> **Pete:** *I had a little hole in my heart, since I was a baby. Since I was born, cos me aunty, she's got it as well. And she gets out of breath as well. ...I can't get a job until the doctor says I'm ok.*

Otherwise it was evident that some of the men were content to be out of paid employment. William, for example, was clear when asked if he wanted to work:

> **William:** *No, not really, I'm not up-to having a career.*

> **Researcher:** What about a part-time job?

> **William:** *Oh I don't know about that, the only work I can cope with is house work. Yes, I'm more like a house man, no, work is not for me.*

Another of the men was more explicit in his response to the same question:

> **Tom:** *No. I don't want work.*

Tom tended instead to focus on relaxation and did not appear to have the confidence to work:

Tom: *I just want to relax and have alcohol.*

To some extent, it appeared that Tom and William were protected from the necessity to work due to their financial circumstances and the supportive framework around them. They shared their own home, which was rented from Tom's mother. They also had access to support from the local authority, who came to the house twice a week to help with cooking, shopping and the budgeting of money. Other men, who also made a decision not to be in paid employment, Sam, for example, had been employed as a glass collector and cloakroom attendant in night clubs. However, he was put off looking for work of this nature due to the pressure and aggression he experienced. He was hoping to find a voluntary job at a local radio station. It was also evident that, in comparison to the other men, Sam had more income, from a trust fund, set up by his deceased parents, which may have protected him to some extent from having to find paid employment:

Sam: *We had loads of blokes there. Cos I was doing cloakroom. I was gonna find all the numbers, cos it's difficult. It was a big place. They wanted 378, I couldn't find 378. Then there was a big fight. I'm waiting for*

a voluntary job on this new radio station. Cross Ribbon City Radio that's
opening up.

Although current policy strongly advocates the promotion and creation of more employment opportunities for people with learning disabilities (DH, 2009), this may not take into account the individual and complex reasons why men (and women) with learning disabilities may choose not to work.

Frustrations and barriers to employment

A number of men experienced different barriers which prevented them accessing their preferred employment options. For example, some men felt their families and carers constrained their employment aspirations. In the case of Ivan, for example, this was a source of frustration and appeared to have a detrimental effect on his psychological state:

Ivan: *I had been offered one job, cleaning the floor like and this sort of thing and I had a row with my dad about it. I feel like he is holding me back.*

Ivan lived with his father, who suffered from depression. Ivan described how he helped his father with the domestic chores, which may have been a reason his father did not want him to work. He also described the strategies

he had developed for coping with the impact of this role on his psychological well-being:

> *Ivan: Dusting now and again and maybe getting a cloth and clean the kitchen floor. Keep some cleaning stuff down, to try and get all the marks off. But I think MIND [charity] are trying to sort a cleaner out for my Dad. It gets me down, that's why I have to go out of the house and have walks and that.*

Another of the men, Jack, was equally frustrated that his work aspirations were not being supported. He was reliant on staff members within his supported living home to help him follow up a potential work opportunity with an animal welfare charity and was frustrated that this had not happened:

> **Jack:** *Like its people not telling me nothing. I'm trying to do things but normally I haven't got any information. Soon I'm going to work with the [charity] and I had a letter and I went up to see them one Saturday. …I'm on my own and they asked me for a letter. People ain't telling me anything. ...The people running the home where I live. I worked with them, you know, people ain't telling me anything. I tried to ring my worker at the home, he's not answering.*

The accounts of Ivan and Jack demonstrate that, despite a willingness to find work, their reliance on others to support them could hinder their work aspirations. The Joseph Rowntree Foundation (1996) has highlighted being reliant on others can disadvantage this group of people, as those around them may have limited expectations of whether people with learning disabilities are able to gain employment.

Part-time, low status work

Acquiring full time work like their non-disabled peers can be an elusive goal for people with learning disabilities. Only one of the men, Harry, was in full time employment (see appendix 12). All of the rest of the men in employment were employed in different forms of part time work. The evidence also suggests that people with learning disabilities frequently have to opt for part time options to protect their welfare entitlement (Redley, 2009). It is for this reason that many people with learning disabilities forsake the risks and financial rewards of full time employment for lower incomes provided by part time employment, which are then supplemented by the welfare state (Redley, 2009). The following commentaries from Rob and Kevin confirm this view. Both of these men were aware that obtaining full time paid employment would affect their welfare benefits. However, they were also aware that they needed to be seen to be in training, or looking for employment, in order to maintain their benefit entitlement:

Rob*: Do the same sort of gardening and get paid for it and that without getting my other money stopped. ...On Mondays I am down the allotment plot through college. ...On Wednesdays I do 'Art Folks' course. ...On Thursdays I do a computer course.*

Kevin: *Well any sort of labouring, fencing and panelling. Well you need a CV and that now. I've done 4 courses with no reply from work places. If I didn't go for them, they might stop my money, do you know what I mean.*

Kevin had not worked for 30 years and demonstrated a frustration related to his inability to compete on equal terms with others in the job market, which resulted from his learning disability:

Kevin: *I can't find the work, Martin. ...When I got to give them my age, do you know what I mean? ...I would take anything, anything as long as it's money, if they offered me a part time job anything.*

Another of the men, Fred, had in the past attended a local social enterprise and used to receive a nominal payment of fifteen pounds per week from this. However, this payment had stopped a number of years earlier. He currently had a Saturday job at a fast food restaurant, sweeping and

cleaning, for which he was paid twenty pounds for six hours work. Although this amount was the apprentice rate and therefore below the minimum wage, Fred enjoyed his work:

Fred: *Yes I clear all the rubbish away, the trays and that and make sure the windows are clean. …They're all friendly there.*

Three other men also worked unpaid at a social enterprise on a part time basis. These men discussed the repetitive and low status nature of the work and also experienced periods of inactivity. The following men found the situation and the nature of the work demoralising:

Researcher: So what are you working on at the moment?

George: *We are doing stinky wipes. Stinky wipes to go on airplanes***.**

Researcher: So do you enjoy it?

George: *Well I don't like it when we haven't got any work in the place. ...We are just twiddling our thumbs. ...It does get me down a bit. I mean*

to say, when you're bored as I am at that time. You can tell when my

face is grumpy and all mardy.

Another man also highlighted his ambivalence to this type of work, particularly during periods of inactivity:

Ivan: *Working here is OK when they've got the work.*

Another man, who also worked at a social enterprise one day a week, preferred to talk about his office job within the local authority, which he did for two days a week. He undertook basic office work and was paid twenty pounds for the two days. He was aware this amount did not interfere with his benefits and he seemed to value and enjoy this work more than the work at the social enterprise:

Derek: *When they've finished in meetings I take them downstairs with*

my ID card. I open the letters and do stamping on the post

These accounts show how gaining full time employment was a challenge for these men, forced in many cases to opt for frustrating part time work to not affect their benefit entitlement (Redley, 2009).

Long-term employment

There are some contradictions within the literature regarding people with learning disabilities and whether or not they are able to maintain employment. Whilst research suggests that people with learning disabilities have problems maintaining employment (Broad 2007), previous research with people with learning disabilities has highlighted how this group of people would like and are able to hold down a range of different types of paid work (Wistow and Scheider, 2003; Emerson, 2005). Five of the men in this study were in long term employment (Alan, Jack, Conner, Fred and Harry) and had been employed for a number of years. This was greatly assisted by the provision of employment advisors; workers employed by the local authority to help these men initially obtain and maintain work:

Alan: *I am in grounds maintenance at Courtfields Crematorium. I am a gardener there ... for about 5 years.*

Jack: *I have been working in a restaurant for about twelve years. I look after the people when they arrive. People coming in, setting all the tables. Set it all up, put the tables all down and then when they're about seven o'clock, half seven, they'd be coming in. They say right they can see it's nice, I talk to people and they talk to me. ...It's a job you have to be careful you know. Well, people coming in and they got hot soup or hot stuff and things like that. I know that. We all do health and safety work that's supposed to be carrying carefully and we get help with that.*

Conner: *I deliver the post to the Sunset House [local authority head office]. ...It was in the city centre, but we're now in the actual depot. It is all the way out at Hall Road. ...We're separate from Royal Mail but they drop off a couple of drops in the morning, and then I just sort it out. [How long have you done that for?] Oh, for about 6 years.*

These previous accounts suggest the men referred to the longevity of employment and the work activities they undertook with a sense of pride, indicating how their work situation can improve their mental well being. Research studies have shown how 'Supported Employment' schemes can add to the quality of life of people with learning disabilities (Beyer et al, 2010). Unlike other men, Harry worked full-time in a supervisory capacity, which he had been doing for fourteen years:

Harry: *I run the warehouse. It's my job title. I help drivers load lorries, sort work out, get the cartons and all the stock. Basically all the duties that would go with running a warehouse. There used to be two of us and then they downgraded because the work wasn't coming in so I got labelled with that. I mean they kept the job but I was actually hoping that they would have deleted my job. And then I would have had my superior's job, which meant I would have got a little bit more money.*

Local Authorities have a responsibility to promote work for all disabled people (Department of Work and Pensions, 2005), which was evident in this study. Remaining in work for a length of time was made possible for this particular group of men through the support and advice from schemes referred to as 'Supported Employment'. Beyer et al (2010) has shown that providing 'Supported Employment', through job finding and job matching schemes, for example, can improve the chances of people with learning disabilities gaining and holding down 'real' jobs. These approaches can help address some of the otherwise disabilist attitudes that can constrain work opportunities for adults with learning disabilities (Joseph Rowntree Foundation, 1996).

Some of the men's accounts reflected the demands on their health of holding down jobs and the need for ongoing support to enable them to do so:

Harry: *I do find that sometimes the job is very stressful and that does affect my health. It doesn't affect me enough to be off work, but it does affect me with severe heartburn or the equivalent is called gastroenteritis.*

Letwin, for example, had a part time job at helping the caretaker at a local

school. His bouts of depression made it difficult for him to seek help and talk to people when work became difficult:

Letwin: *Last winter I felt rushed off my feet. ...Cos they lost the caretaker. He had to be assigned other duties. The other person stepped in his place to do his job and everything was all over the place.*

Researcher: That sounds stressful. Did you have to hold that in until you had a chance to talk to the person who was monitoring your workplace?

Letwin: *Yes I did. ...I did eventually mention it to the actual person at the school. You know I would only talk to people I would want to talk to about these problems.*

Two other men were positive about their employment. Norris, for example, liked the fact that his manager understood that he wanted to work with his girlfriend:

Norris: *I work at Kingshill Nursery. ...Well, we do plants. Clean up plants and things like that you know, keep them tidy. The boss is very nice. ...I work with [girlfriend] ... I sit with her every day. The gaffer says, "I don't mind you doing that". It's alright. He's quite nice about it actually.*

Another of these men also had good relationships with the management at his place of work:

Mark: *We've got labels and we just stick them on the baked bean pots. Stick one label over the back and then one label over the front.*

Researcher: And do you enjoy that?

Mark: *Yes I do. The gaffer says I'm a good worker, Get on with my work. Don't argue with anyone at work. If he gives me a job, you just do it. ...He shows me what to do. "Do this", and I'll sit there and say, "Is that right?" He goes, "That's right, you've got the job". He says, "Just keep doing it all the time". So when I go in the work every day, I've got different jobs to do. ...We do boxes. Make boxes up. Dividing trays up.*

These two men, Norris and Mark, lived in the same independent supported living home together and their work was provided through the organisation that ran the home. They were both paid £20 per week and were content with this amount:

Mark: *Yes we get paid on Fridays, I like where I am.*

Norris: *It helps me yes. Buy things that I like if I want to buy something…*
you know, what I mean I can.

Similar to Norris and Mark, another man also showed that work can be positive for this group, particularly when the work suits the ability of the individual and the right level of support is in place. Oliver had just started a trial period for a job at a local supermarket, which had been found for him by his employment advisor:

Oliver: *I'm doing work placement at [supermarket]. … Its warehouse work, stacking shelves. Not just stacking shelves, like getting stuff off the lorries and making sure it's comes to like (supermarket) and all that.*

Researcher: So how long have you got to do that for?

Oliver*: It's for 3 months and if they think I'm any good ... they might put me on as a full time employee. ..Yes, they're telling me bits and bobs about how I'm doing and like, if I'm slacking or not paying attention and everything.*

Other research with people with mild learning disabilities regarding the benefits of employment support and advice has shown that it can improve

their individual self development and mental well being. In a study by Cramm et al (2009), people with mild learning disabilities stated they enjoyed the social interaction and integration that being employed can provide. They also highlighted that work can help them feel appreciated and important. The following account, from Jack, confirms this type of confirmatory affect of employment:

Jack: *I enjoy it. ...I work outside you know, cleaning up, cleaning down. Put all the lights up for Christmas, around the area, around the door. Helping the managers. Talk to the managers. Sitting down. Talk to the other managers about what we are doing. There are three managers and the secretary. ...I can support them too, patients with learning disabilities; you know when they have blood tests.*

The men in the study revealed a complex picture to how they perceived and experienced employment. Men showed the capacity to contribute to and maintain different forms of employment over a number of years and expressed the enhancements to their mental well being of doing so. However, finding and sustaining suitable employment options for these men, would not be possible without the support of specific local authority schemes, schemes which are not universally available to all adults with learning disabilities (Beyer et al, 2010). Some men chose not to work and others reported how their learning disability related conditions impacted on their opportunities to work. However, low paid, part time and demoralising

employment/unemployment circumstances characterised the experience of most of the men. This, in addition to the disabilist barriers and men's employment opportunities (Joseph Rowntree Foundation, 1996), not only contribute to a negative impact on their psychological health, but also confine these men to a reduced socio- economic position. The chapter now moves on to explore a critical aspect of relative poverty, which is, living in deprived areas and its potential impact on health.

Living in deprived neighbourhoods

 A further consequence of the low incomes and limited employment opportunities experienced by men with mild learning disabilities concerns the nature of the neighbourhoods in which they live. To date, research regarding neighbourhood and learning disability has focused on the negative neighbourhood reactions surrounding homes for people with learning disabilities (Robertson et al, 2005), and the hostility towards people with learning disabilities (Collins and McConkey, 2007). However, studies have not focused on experiences of people with learning disability regarding the neighbourhoods in which they live. This is despite the evidence which indicates that people with less profound learning disabilities are more likely to be living in socially deprived areas (DH, 2001; Leonard et al, 2005; Emerson and Hatton, 2009). The Indices of Deprivation (Department of Communities and Local Government, 2007) is the main measure of deprivation in the UK. According to this index, all of the areas in which these men lived, with the exception of Conner, whose rent was paid by his father,

and the four men living with their parents, were defined as socially deprived (as indicated by postcode). Moreover, the accounts of those men living independently revealed a sharp appreciation of negative experiences associated with living in neighbourhoods categorised as deprived, including threats to their physical safety and psychological well-being.

Threats to physical safety

The men were aware that the police may visit the area in which they lived more often, for a number of reasons. The men referred to different occasions when they felt threatened. This is particularly evident in the following extract:

Kevin: *We had the windows put through and it was terrible. ...Police come out and he said, "did you see anybody?" I said, "no didn't see anything". ...It didn't stop [noise from neighbours] until about three in the morning, until they come and boarded it up. You got to wait five working days before you put your new window in. ...Oh, terrible it is and then one day, round the wash line, Martin, they [youths] were dumping motor bikes round the washing line, about half a dozen of them. You know, you couldn't even hang your bloody washing out, do you know what I mean. I reported it to the police. There's about half a dozen bikes outside the washing line. They come out and took them away.*

The men were also aware that the police would prioritise certain incidents and that these could occur in the area they lived in. In addition, another of the men was of the perception that police involvement generally referred to incidences of a serious nature:

Pete: *Well the only time they'll turn up is if someone's got a firearm on them. That's the only time they'll turn up.*

Another of the men, Harry, described an incident with the police in which he felt he was a victim of the negative perceptions associated with people living in a poorer neighbourhood:

Harry: *I was coming home through a back alley from where my parents live, cos they live in Sherwood Heath. And I had all bags on me like. Anyway he [police] stopped me and he said, "Where do you live?" I said, Hayley Hill. And he said, "whereabouts in Hayley Hill" and I said Farmers Close. He went oh. ...I said, oh, so I live there and then I must be a burglar ... I was really pissed off. Because I was sort of just leaning on the handlebars of my bike like this, you know.*

Harry went on to describe how he felt his personal safety was at risk due to a violent neighbour:

Harry: *There's a chap that lives on the third floor who I've seen go up and hit the door of number Twenty-Five with a hammer. I don't particularly like the idea of him going round with a bloody hammer and he's smashing on the door like that.*

Resilience

Whilst the previous accounts represent levels of anxiety resulting from violence associated with living in a deprived neighbourhood, they cannot be explained by timidity, which can characterise this group of men. It was also the case that men in the study felt they had to learn how to stand up to others within the area they lived:

Oliver: *I've just been brought up to fight basically, to stick up for myself. Cos like I can't depend on my parents all my life. One day they're going to be dead. ...I've got to stand up to challenges round here.*

As evidence of this, Oliver, the youngest man interviewed, described a time when he confronted his grandmother's partner for misleading her with medication, which resulted in this man physically threatening him:

Oliver: *He put my Nan on these medications, making her go all funny and he was like he was manipulating her. He like tried to get me by the*

scruff of my tee-shirt, clothing and he was holding me to the wall saying,

if I ever do anything like this again, he'll kill me.

Similarly, Harry showed a degree of resilience in relation to living in a 'tough' neighbourhood having reported his neighbours for noisy behaviour. However, he was also conscious that he then had to avoid this neighbour:

Harry: *Because I've reported them. ...And that's why they don't like me. You see a lot of people won't do what they say. I do what I say. But I mean, yes, I often thought, will I get any comeback? But I never got any comeback. So I mean I think you know ... I mean if they, you know, kick the door in or something like that, I get the police. It's another one [neighbour] I avoid.*

Pete who had felt intimated in his previous flat continued to be exposed to anti-social behaviour in his new flat:

Pete: *When I first moved in, it was bit noisy, playing his music and that. ...When you woke up Sunday morning, about quarter to two, the car park was full. ...His mates actually drove on the grass and parked out the front here [in front of his kitchen window]. ...Two lads kept banging on our window asking for a cigarette and in the end they just put it through.*

On this occasion, however, he had the confidence to take a photograph and considered showing it to the local neighbourhood officer:

Pete: *I took a picture of it because it was dark it didn't turn out that well. ...I would have showed it to the girl, she's the housing officer. If I hadn't took that picture… she wouldn't believe me, or anyone would believe me.*

Oliver, Harry and Pete all showed a level of resilience in the way they tried to deal with living in their neighbourhoods, in the face of intimidating circumstances. This is confirmed by other studies showing how men and women moving out of both 'long stay' institutions and the family home have learned to cope with stigmatising comments from people in their neighbourhood (Jakoda and Mahoda, 2004). Other accounts highlighted the stressful nature of living in deprived neighbourhoods and the negative impact this had on their psychological health. These accounts demonstrate a new insight into how men with learning disabilities cope with living in areas of relative poverty.

Threats to psychological well-being

One of the men, Pete, had recently moved into his current accommodation shortly prior to being interviewed. Both his previous and current flat were located in socially deprived areas. His reflections on his previous home revealed an appreciation of the stressful nature of the neighbourhood he lived in and how he continued to feel threatened:

Pete: *It was just the neighbours around there playing music too loud and shouting and putting windows through. It happened here again after that as well.*

Pete highlighted the negative impact that living in these circumstances had on him:

Pete: *Yes when they [the lads] were coming around I felt intimidated. ...Yes, that's why, if I want to go out and that, and they're outside, I just wait until they're gone.*

Researcher: That must have been stressful*?*

Pete: *Yes that is why my high blood pressure goes up and the doctor signed me off [work]*.

Although this physiological reaction could be linked to the fact that Pete had a hole in the heart, this comment illustrates how he perceived the negative impact on his health from living in a deprived neighbourhood.

Another man reported similar experiences of feeling unsafe in his home and neighbourhood. Jack highlights how he felt when potential burglars had come into his garden:

Jack: *People jumping over into the garden and cutting the wires [to the security light], you know and nicking the outside light.*

Researcher: When they did this how did you feel?

Jack: *I was frightened; I was more frightened when they jumped over.*

A number of men also experienced illicit drug use close to their homes. Pete, for example, discussed how people openly smoked drugs in the communal entrance hall of his maisonette flat:

Pete*: Smoking stuff, like cannabis in the blocks.*

Another of the men highlighted how drugs were being sold elsewhere in the block of flats where he lived, but he felt unable to intervene:

Rob: *No. No I keep my door shut. Keep it locked, keep my nose clean and that. I don't want to get involved in them.*

Emerson et al, (2009) illustrated the widespread negative impact poverty has had on the life experiences of people with learning disabilities. The findings in this chapter extend that work, highlighting how these men experienced physical threats to their safety and the adverse psychological effects on their health associated with living in deprived areas.

Conclusion

This chapter explored how men with learning disabilities perceived and experienced the impact of relative poverty on their health. It has shown how income, employment and their local neighbourhoods, all play a significant role in how men live through and make sense of their relative poverty, which have implications for both physical and psychological health.

In terms of income, the men not living independently were unconcerned about their dependence on others for financial management. However, this situation confirms existing research (Brown, 2010), in that men were left vulnerable to financial abuse and potentially trapped in sub standard care, without the financial control to alter their living arrangements. The men living independently expressed how their reduced income meant they lived in fear of debt and had to survive without basic items. The men were forced to adopt methods to try and overcome their financial hardship. Significantly, the accounts revealed new insights into how the men had to 'get by' on a daily basis with the impact of their reduced socio-economic position, all of which had negative effects on their psychological and physical health.

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The men revealed varied perceptions and experiences of employment. A few men chose not to work or were prevented from doing so because of health conditions. Significantly, the employment situation for most men was characterised by part time, low paid and low status work. The low status work and lack of control over it undermined men's psychological well being and confirmed research showing how the stress involved is associated with longer term poorer physical health (Marmot and Wilkinson, 2005). The chapter shows how disabilist barriers to employment opportunities converge with the men's reduced low income, demonstrating the associated effects of disability and relative poverty on their psychological well being. However, when specific employment schemes were put in place for the men, the accounts contrasted with existing research (Broad, 2007), demonstrating men were able to hold down work over a prolonged period of time and contribute to the workplace.

The men revealed an incisive grasp of the challenges associated with living in deprived neighbourhoods. The accounts begin to unravel the negative impact on their physical and psychological health, which results from living with the constant threat to themselves and their properties. The findings add new insights to how the men experience the harsh reality of living in 'tough' neighbourhoods.

Overall, the chapter has demonstrated how drawing on feedback from men with learning disabilities themselves, deepens understanding of how specific aspects of relative poverty, have adverse implications for their health. In doing so, the findings have revealed significant new insights into the challenging social circumstances this group of men are faced with on a daily basis. The next chapter will address another key social division affecting the health of this group of men; reporting on how men perceive and experience the impact of masculinity on their health.

Chapter Eight

How men with learning disabilities perceive and experience the impact of masculinity on their health

Introduction

This chapter provides an analysis of the third and final social division affecting the health of this group of men, namely gender. As highlighted in chapter four, gender is an essential factor shaping the lives of men (Doyal et al, 2009).The chapter explores how men with learning disabilities perceive and experience their masculinity and its impact on health. It is divided into three sections. The first section explores the different ways in which the men understand and express their masculinity. It shows that the men were aware of many of the traditional practices and roles associated with being male, such as being the 'provider' within the family. It also reveals how this group of men consider the varied forms that masculinity can take and its impact on both themselves and women. The second section focuses on how these men emphasise the importance of taking responsibility for their health. As such, it moves away from much of the dominant thinking regarding men's behaviour in relation to health (Courtenay, 2011; DH, 2008b). These men also recognised the practices other men often adopt that potentially can harm health, such as excessive alcohol consumption. The concept of 'hegemonic masculinity' (Connell, 1995) is employed to assist understanding of their accounts. This provides understanding regarding how this particular group of men perceive masculinity and how, as a vulnerable group of men, they may experience the oppressive practices of other men.

The third section examines how these men view and experience the association between masculinity and health promoting behaviour. These men are able to demonstrate an acute awareness of certain health conditions, in particular illnesses associated with a range of health damaging behaviours. The findings show how this particular group of men distinguish themselves from other men, in the ways they recognise the need to seek health professional advice and act upon it. The chapter concludes that despite their inherent cognitive difficulties, these men presented a nuanced account of masculinity and its impact on health.

Understanding masculinity

Physical prowess and gadgetry

As discussed in chapter four, there has been a conceptual shift in understanding, which has resulted in the notion of masculinities that better reflect the plurality of male identities. However, no literature has been found that explores how men with learning disabilities understand and experience masculinity and its significance for health. Therefore, all of the men were asked what they thought masculinity meant to them. Their accounts demonstrated a varied view of 'being male', albeit within the context of certain hegemonic ideals concerning masculine identity. Many men, for example, equated masculinity with undertaking sporting activities, particularly bodybuilding:

Norris: Men *do sports, football, and rugby.*

Conner: *Its two extremes. It's like David Beckham who is really sporty, more athletic. Then body builders with muscles up to here. …It's more sort of they like to show off.*

Letwin: *Men like building up their muscles.*

These accounts resonate with other research that has identified sport as a key marker of masculinity, which is intrinsically structured into boyhood culture (Messner and Sabo, 1990). Thus, men who build their bodies are externally showing how they are living up to gendered stereotypes of being 'tough and physically strong', thereby demonstrating masculinity (Courtenay, 2011: 32).These men not only recognise these as things that men do, but also how they demonstrate other aspects of masculinity, such as physical toughness and strength. This is illustrated by Oliver when he discussed playing Rugby at school:

Oliver: *Yes, I played a couple of matches, I had like a few bruises on me and that but it doesn't hurt me.*

In a similar vein, Brian described how he had been able to build up his

upper body strength through being a wheelchair-user, developing the muscles in his arms:

>   **Brian:** *I am quite muscular at the top here* [*pointing to his bicep area*], *from pushing myself around all the time.*

Similar to Brian, Oliver also saw himself as physically strong:

>   **Oliver:** *I'm like a very active person. I'm like strongly built. I like to, what's the word, I like physical challenges.*

However, men also recognised that they often did not live up-to these masculine ideals:

>   **Harry:** *Masculinity would be muscley, which I'm not.*

One of the men, Conner, also believed that men's desire for a good body shape was principally to attract women:

>   **Conner:** *I think in this day and age everybody wants a good body shape. Some men want to have, how we shall say it, a more refined*

body shape. …To try and impress the ladies.

However, men did not perceive that maleness could only be demonstrated through playing sports, or building up their bodies. Some men differentiated themselves as men through their command over and appreciation of gadgets:

Conner: *Well I have always been into playing video games, but for the most part I am more of a gadget man.*

Letwin: *I am gadget man. I have an ipod and I am saving for an ipad.*

Men's apparent preference for gadgets is illustrated through the heavily male dominated information technology industry, which also demonstrates how technological competence is considered a feature of masculinity (Comeau and Kemp, 2007).

Hiding or showing emotion.

Similar to their discussion on body building, sporting activities and gadgets, these men were also able to identify other culturally dominant masculine traits (Pleck, 1994). As such, men put forward certain practices that have

been identified as core aspects of hegemonic masculinity, such as not showing emotions and taking risks (Courtenay, 2011):

> **Harry:** *I think a lot of guys don't like to be seen crying. Or they don't like to be seen as being weak. I suppose I don't show my emotions, I hide them. But I do have them.*

This comment from Harry endorses the masculine practice of emotional containment while also acknowledging the social pressure of having to conform to norms of masculinity. Thus, while expressing the fact that he does have feelings, he associates revealing emotions as being weak. Similar to Harry, Norris was able to identify another way in which men demonstrate masculinity, namely risk taking and driving fast:

> **Norris:** *Men drive faster than ladies. …Because they're masculine.*

Men were also aware that certain aspects of masculine identity were apparent in the ways in which men demonstrate their dominance over women, though they recognised this was not straightforward:

> **Harry***: For men who think they are superior that's where the problem is. Men think they have to be one of the boys. But from the women's point of*

view, he is just showing off. Just being manly. You try and show too

much of the other side [being sensitive], it's hard to get the balance right.

Oliver believed another way in which men expressed their masculinity resulted in men taking sexual advantage of women. His comment showed how he felt some men held limited respect for women when behaving in this way, though here again he recognised that being a man was not all about dominance:

Oliver: *Well it is like sexual stuff and getting women pregnant. ...Some men just take the piss out of women for a laugh. Just to be a man I don't think like you have to be all macho and tough.*

Thus, men were able to demonstrate more nuanced appreciation of masculinity. They were also able to recognise how men could show masculinity in different ways in different contexts (Coles, 2009):

Derek: *All men are different. ...I have a special nephew, I am his god-father. ...I look after him and give him special cuddles.*

It was also apparent that they recognised how men could take on caring tasks, demonstrating a 'softer' more sensitive side in the home environment:

Jack: *Being a man is like being a lady. Well men are looking after the children as much as the ladies.*

Thus, in opposition to the 'strong silent' male stereotype, these men also recognised that it is important for men to be more 'open' in the sense they should talk when in a relationship, which was also perceived to be better for men in general:

Jack: *Having a relationship with his wife. They talk about if they want kids or not. They like sharing or talking. Do you want to work or you don't want to work? She might have a problem? She can't have kids. That's why you should talk about these things then, it makes it easier.*

Also apparent were the ways in which the different arenas that men inhabit, presented different opportunities for them to demonstrate their gender (Courtenay, 2011). The workplace, for example, was one site where men could clearly demonstrate their worth as men (Saltonshall, 1993):

Rob: *I don't like to be stuck at home looking at four walls. I have done that enough in the past. ...I like getting out. Some men just stop in bed.*

Work was also identified as an important setting in which men could demonstrate masculinity in terms of physical ability and control. The following comments echo other research which has demonstrated how work may provide men the means in which to demonstrate their physical strength (Dolan, 2011). These comments also show the importance of keeping fit and healthy to be able to function effectively in certain workplaces (cf. O'Brien et al, 2005):

Oliver: *I am getting stuff off the lorries and making sure it comes into the supermarket properly and all that. …It is like, very physical and very tough. It's fast, very fast handling work. You have to be quick and very strong. So you have to have your head in the game.*

Letwin*: It is important to build your muscles up to give you strength if you work in a physical job. ...A lot of jobs out there are physical and some workplaces provide physical activities.*

Perceptions of men's multiple roles within the family

Men were perceived as adopting traditional male practices within the family, which provided another facet to their understanding of masculinity. When asked whether they thought working and bringing money into the house was important to being a man, the following accounts reflect how a number of men identified the provider role as important:

Kevin: *When a man's a breadwinner like when my dad was working, he used to bring the wages in, smack them on the table and say what was his, what was ours, sort the bills out and that's how I look at it.*

Pete*: Some men have jobs, don't they? ...Because they bring in the money.*

Men were also able to articulate why men needed to bring money into the home:

Kevin: *They've got to keep a roof over their head, pay the rent and the bills. If you have a baby to look after, you have to buy nappies. You've got to bring the baby up.*

Tom: *Oh definitely important, so they can pay the bills in the house.*

Some of these men aspired to the role of breadwinner. One man, who had a family but who was not in paid employment, was keen to demonstrate how he wanted the opportunity to fulfil this role. He viewed this as a fitting way to live up to masculine ideals:

Rob: *If I had a real job, I'll have a go at bringing the money into the house. Yes, that's something to look forward to in the future. I do try and bring some money into the house for us. I would put it aside in a tin or maybe a bank account or something.*

Alongside the role of the provider, some men recognised the male role of protector as important within the family. This was most apparent regarding Oliver, whose father had left his mother and younger sister the year before being interviewed:

Oliver: *I'm not a hard man. I'm as soft as they come. But if anyone hurts my family then I will get violent.*

These accounts demonstrate the perception of men as protectors, in relation to women and families. Brian thought it was important to keep fit and healthy to be able to help his mum around the house, as well as being able to protect those closest to him:

Brian: *It's important to look after yourself. Some men do weightlifting. …Specifically if their partner gets into trouble, they are able to defend them then.*

It was also the case that one man's experiences of trying to live up to the responsibilities and behaviours associated with fatherhood, could impact on his psychological health. Rob was unique in the study, being the only man with a partner and a daughter. When asked how he felt about being a father, he was positive, but recognised that it was not always straightforward:

> **Rob***: I like being a dad but she's [daughter] been told to leave me alone when I come in every Monday. Let me have five minutes for my bag and that. Take my boots off, then come down stairs, sit down and have my dinner. Once I have had my dinner, then she can play with me.*

This extract also echo's existing research, which highlights men's main parental role as play-makers rather than direct caregivers (Rongfang and Schloppe-Sullivan, 2011). However, Rob tried hard to do 'dad things' with his daughter, taking an interest in her and revealing clear attempts to take his role as a father seriously:

> **Rob:** *I take her over the park, we have a picnic over there and then one of the days me and her are going to the swimming pool. ...I take her up the Hatchford Park. She likes going there. There are the pipes with water coming down. ...On Fridays she stops behind and does gymnastics and then afterwards she goes on the bikes, she likes that.*

Research on the general population has highlighted the multi-dimensional influence the father can have on his daughter's future psychological development (Gallagher, 2008). The way in which father and daughters negotiate relationships has been shown to influence the daughters' self esteem, attitude towards success, sexuality and body image. However, on further questioning, Rob indicates how his relationship with his daughter is sometimes problematic:

Rob: *Well, I wouldn't say it was too difficult. I know me and my daughter can have our ups and downs, but we still get on. She says sorry, I'll say sorry to her. We both have a cry and then we're alright.*

As indicated earlier in the chapter, not showing emotions is a core aspect of hegemonic masculinity (Connell, 1995). However, that Rob feels able to discuss his emotional state in this situation, is possibly associated with his higher susceptibility to stress, as a learning disabled man (Cooper et al, 2007). This is further illustrated by his following comment. While Rob tried hard to be a good father, there appeared to be a build-up of stress associated with bringing up a young child and maintaining his relationship with his partner, which Rob appeared to find difficult to cope with:

Rob: *Yes when I get wound up and stressed and that, I go out. ...They do get at me and I know my partner has told me to calm down and she*

does her best with me and that.

Furthermore, having initially asserted that it was not too difficult being a father, Rob went on to describe an incident when it became too much and his daughter was taken from him for a period of time:

Rob*: I didn't know who phoned the police. Cos we had all the windows open and I said to her [daughter], or somebody heard me shouting; "I'm going to fucking kill you" and then they phoned the police. Six police cars out there and they all came to my door and came in. …They didn't take me away. ...My partner was just going at me and Social Services were involved and took my daughter away for a while.*

This extract shows how Rob demonstrates his masculinity in terms of anger, when feeling under pressure. Men are reported to express their distress differently to women, for example anxiety, anger and low mood (Ridge et al, 2010). However, studies related to emotional distress have tended to focus predominantly on women (Rogers and Pilgrim, 2003). Keeping their emotions intact and not talking about how they are feeling, is a clear way that men demonstrate masculinity (O'Brien et al, 2005). The following account reiterates this notion, while not excusing his behaviour, Rob evidently felt unable to reveal how difficult his home situation had become and had allowed his feelings to build up:

Rob: *I had never felt like this before, it just got too much. ...It was just stressful inside and I couldn't cope.*

Studies have shown how the presence of fathers who experience high level of parenting stress maybe detrimental to child health (Lee et al, 2008). However, in this case, Rob is a man who is competing with multi- faceted psychological pressures. As shown in chapters six and seven, poor coping mechanisms, associated with learning disability, low income and evident attempts to live up to the pressures of fatherhood may have represented a triple jeopardy in this case (Rosenfield, 2012), with adverse effects on his health and the well-being of those around him. Thus, his account suggests how the interplay between disability, relative poverty and gender can have a negative impact on health.

Some of the men also identified independence as a feature of masculinity. This is in keeping with wider research, which has found that boys and men experience greater social pressure than women to live up to masculine ideals such as being independent and self reliant (Courtenay, 2011). In addition, in line with policy initiatives (DH, 2008a) and the wider personalisation emphasis (Ministerial Concordat, 2007), it is also increasingly expected that men and women with mild learning disabilities will live independently, away from parents and/or other forms of paid support. Thus, William, for example, who lived with his friend, associated being independent as an important male characteristic. However, he felt his

friend's mother's interference in their lives had reduced some of their independence. Therefore, while William is attempting to keep up with what he constitutes male behaviour, he has also to contend with possibly disabilist expectations, regarding difficulties associated with learning disability. This encompasses other people's perceptions regarding the reduced coping strategies associated with learning disability, which may prevent him from living on his own:

William: *Well she has took her son's independence away and now she's trying to take mine.*

Researcher: So you feel she is doing too much for your friend?

William: *Yes, because I'm trying to be independent and she's not allowing me. ...When I first became independent was when I first moved out of my parent's house and that's when I became a man.*

William's comments also demonstrate how he related masculinity to being in control and his sense that this was threatened was a source of frustration:

William: *Being a man means you got to take full responsibility in your own life. ...She's always doing it. It means she is overprotective. ...Sometimes I get angry and frustrated. It's upsetting me inside.*

The previous accounts reveal how these men, in spite of their learning disability, showed a good appreciation of the ways in which men understand and perform masculinity, demonstrating that masculinity is a pertinent issue for men with learning disabilities. These men recognised the masculine role as provider/protector within the family, which many aspired to fulfil. In these ways, these accounts add to the picture of how men attempt to live up to certain masculine ideals. These findings, therefore, provide new insights into how men with learning disabilities understand masculine ideals and the varied ways in which their experiences as men are shaped by their learning disability and societal reactions to that. The chapter now moves on to consider how they considered other men behave in relation to health.

Male health-related behaviour

Experience and perceptions of health damaging behaviour

As highlighted previously, enacting a masculine identity has been highlighted as a potential health risk for men (Courtenay, 2011). Men have been found more likely to adopt health damaging behaviours, such as excessive alcohol consumption, smoking and engaging in high risk activities, such as fast driving (DH, 2008b). In light of this evidence, all of the

men in this study were asked about how they perceived men behave in relation to their health. Most of these men believed that men generally did not behave in ways that were health promoting, particularly in relation to alcohol and smoking, which they linked to certain health problems:

Rob: *Men can die from liver disease, drinking too much and smoking.*

William*: Alcohol can affect your liver, it's a dark poison.*

Harry: *Well you could say drinking and smoking yourself into an early grave.*

Letwin: *They keep getting trashed out of their face. ...Smoking is bad, it's vile.*

Some men had first-hand experience of the damaging effects of alcohol. Jack described being physically abused by his father when he was younger and realised the destructive effects of alcohol:

Jack: *He was a nasty bugger. He was drinking all the time. ...My mum passed away, I had to look after my sister, my brother. It was too much and they got beaten. ...I called the police and they had him up in court.*

This account from Jack resonates with wider research on the relationship between child abuse and parental alcohol misuse (Widom and Sturmhofel, 2001). It suggests that how this particular population are more susceptible to different forms of abuse in general (Anne Craft Trust, 2009). It also illustrates how men may not seek to express their masculinity in the same ways. In the case of Jack, he did not drink alcohol but did think that being physically strong and able to fight as important masculine attributes; "*You have to be able to look after yourself*".

Perceptions of alcohol consumption and associated masculinities

The men also made the link between how alcohol could lead men to behave violently towards women and other men:

George: *It's like they are violent with them and hitting and pushing them around. If he's had too much to drink and then his wife says; "I'm not touching you" and then he gives her a slap in the face. They sometimes don't stop. Just full speed ahead don't they.*

Pete: *On a Friday or Saturday night and they had a few, it can all kick off.*

Following on from this, Pete discussed how men behaved with other men in relation to women when out drinking:

> **Pete:** *If they've got a girlfriend and another guy looks at her in the wrong way, that's all it takes. The guys looking at another man's Mrs's or wife or what. And that's how it kicks off.*

Other studies have highlighted how alcohol can fuel violence by men against their female partners, which also appeared to be used to demonstrate their dominance as men (Peralta et al, 2010). The previous accounts echo this research and show how these men have awareness regarding how alcohol can fuel violent expressions of masculinity. In a similar way, George felt that the issue of men, who consume too much alcohol and then behave violently, was related to men demonstrating such aspects of manhood:

> **George:** *They start getting violent with people. ...Yes they think they're tough.*

It was not only alcohol that could make men violent:

> **Kevin**: *I mean these men, they've got no money they would rather be smoking the whacky backy. That does them no good either. It can bring on an argument.*

Letwin described a time when he had been offered marijuana, but refused. He was aware of the potential negative effects of such substances on his underlying health problems:

Letwin: *This chap offered me marijuana. He was smoking it. I thought I might want to try it out, with me being a non smoker perhaps try it in a different form. But I had heard its best not to be taken, as I do suffer with bouts of depression.*

Other men revealed a different experience related to alcohol consumption. In contrast to previous accounts, Tom and William did admit to drinking alcohol on a regular basis. William also appeared to express his masculinity through the amount of alcohol he drank, in the sense that he perceived himself as drinking the same amount of alcohol as other men:

William: *I normally have three cans of beer a day. ...Well I sometimes know I can tell lies, sometimes I have about five. A man normally drinks about five alcohols.*

Both Tom and William were also aware of the potentially unpleasant effects associated with alcohol. Tom, for example, recognised that too much alcohol could have an adverse effect on how he interacted with those

around him; "*I have known to be awkward*" and he also referred to the time he drank too much:

> **Tom:** *Well I like going into town to the Dog and Fish pub. ...One time I was ashamed of myself. I had 10 pints and I staggered home and fell down.*

George was also aware that some men were not able to control themselves, once they had started to drink:

> **George***: Well when they're in the pubs and they have had too much to drink and got themselves drunk. ...It's usually too much whiskey or whatever they drink. They say I'm going to carry on, but they have to carry him all the way home so he can sleep it off.*

Perceptions of drinking alcohol in public

A number of the men equated socialising with drinking. It has been suggested that the British public house is a rich cultural setting that can provide a sense of community for many men with advantages to mental well-being (Orford et al, 2009). However, the 'male pub culture' also provides evidence of excessive alcohol consumption, which has been reported as an ongoing concern for governments, reiterated in alcohol

reduction strategies and the changes to opening times within public houses

across the UK (Department of Health, Education, Skills and Culture, 2007).

This was the case with Jack who adopted what he believed to be customary

male health related behaviour, watching his local team playing rugby and

then meeting his friends at a pub:

Jack*: I watch the team every Saturday. I've been watching them for a*

while. I go with them and stay with them. Have a good drink. Have a

good time with them.

Researcher: So do these friends live nearby?

Jack: *No, they are friends I meet in the pub. I go to different pubs. They*

buy me a drink. I buy one back. It's easy like that.

The pub appeared to provide Jack with an opportunity to meet and bond

with other men, overcoming potential social isolation (Pease and Pringle,

2001). However, for other men, the experience of going to the pub could

make them feel vulnerable. Brian, for example, admitted that his fear of

getting into a fight at a pub was the primary reason he drank in the house:

Brian: *I don't like going to the pub. ...When people drink too much they get rowdy and get into fights. ...I wouldn't want to get caught up in it.*

Conner only went to the pub early as he did not like the crowds:

Conner: *I do tend to feel a bit, what's the word I'm looking for, a bit hedged in. I go earlier, at the weekends it can get really busy.*

In comparison, Tom and William, who were two men who reported drinking on a regular basis, expressed no such concerns about visiting the pub, which they described as their main social activity:

Tom: *I prefer to drink pints up the pub or cans in the house. I go to the pub with my friend William.*

As noted previously, William was aware of the effect alcohol could have on him and this often made him feel unsafe. In part this was the reason he would not go to the pub by himself, but he also recognised that should he be affected by alcohol, then his friend would be there to help him:

William: *I would never go there on my own. ...The last time I went with Tom, I always drink too much alcohol.*

Researcher: So are you worried about what other people might do if you are drunk?

William*: Yes, I might get wobbly and lose my focus. Too much alcohol can be dangerous can't it?*

William described an occasion when Tom was not with him and he got barred from the pub:

William: *I was having a cigar and drinking, drinking too much alcohol*

. ...And the landlord said; "You cannot come back in here again".

Evidence from other studies suggests that men's ability to consume alcohol can be a means by which men demonstrate their masculinity (Dolan, 2011). However, whilst the previous accounts suggest that some of these men did seek to conform to such masculine ideals, their accounts also reveal that these men are aware of how drinking excessively in public, exposes their vulnerability as learning disabled men.

In a similar vein, whilst a number of these men aspired to finding paid employment as a means of fulfilling certain hegemonic aspirations, it was also the case that men showed how experiences and perceptions of employment can have a negative impact on health. The following man, for example, was able to identify the strain he associated with working long hours and being a 'bread winner':

Tom: *Men can get stressed and tired. ...And frustrated.*

In addition, men also understand the negative psychological impact if men were unable to gain work:

Kevin: *Well some men find it difficult because they ain't got a job. Some men can say; "I ain't got a job, I've got no money coming in", and that's why they are miserable.*

Another man, Norris, was aware that unemployment was currently rising:

Norris: *There is less work around at the moment.*

As chapter seven has shown, certain health conditions associated with

learning disability could negatively impact on the employment and employment opportunities available to these men. The previous accounts reveal a further layer to their perception, in that some men were able to understand the negative psychological effect unemployment could have on men and how this could damage their sense of masculinity and well being. Norris, for example, was also able to recognise how being out of work could 'upset' men and this was linked to other adverse effects; "*Some men do get violent*". The negative impact of male unemployment on female partners was reiterated by another man:

Kevin*: If you've got no money coming in and you're libel to get evicted and you can lose your furniture and other stuff. Men can then take it out on somebody else, get into argument with the wife or girlfriend.*

Thus, there was some recognition that it is not only men who are ultimately affected by male unemployment. These previous accounts amplify other research on the negative impact on women's health resulting from male unemployment (Silberschmidt, 2001). As such, these accounts also resonate with research which demonstrates how patriarchal male behaviour can adversely affect the physical and psychological health of women (Walby and Allen, 2004; Humphreys, 2009).

Vulnerability and other men

It is generally recognised that people with learning disabilities are amongst

one of the most vulnerable groups within society (DRC, 2006). A number of men described different incidents where they experienced fear and threats, which was also evident in the case of Jack, who felt somewhat protected by his physic; "*You can still get into a fight if you are big and strong and still get hurt".* Sam, for example, highlighted an incident when he was mugged at knifepoint:

Sam: *It was dark and it happened when I was on George Street. ...They took money off me. They did not stab me, but they would have done***.**

In light of his experiences, Sam was aware of the need to exercise caution when out walking:

Sam: *It like could happen when I am out wandering around. ...I am still going to carry on I just need to be very careful*.

However, this extract also highlights how Sam, whilst evidently scared by the event, was keen to point out that this would not change his behaviour. Thus, whilst his inability to defend himself during the attack potentially assigned him to a subordinate masculine position, he continued to fulfil other aspects of dominant masculinity in his assertion that he would continue to walk the streets, regardless of the potential dangers.

It was not only in public arenas where men felt vulnerable. The following account shows that this could also occur within the learning disability community. For example, one man described how he was picked on by other men with learning disabilities at the day centre he attended:

Derek: *Well people do pick on me and it makes me lose my temper. ...They wind me up and say nasty things. I do walk away and try and ignore them, but they just carry on.*

Researcher: Does it bother you that they tease you?

Derek: *Yes it does. They tease me about my hearing aids.*

Derek's account also echoes other studies which uncovered a hierarchy amongst people with learning disabilities that existed in the long-stay institutions during the 1950s (Martin, 1984). This work illustrated how other more able men within the learning disability community could exert influence over other less able men, often resulting in better work opportunities for themselves.

In addition to physical threats, a number of men discussed situations where they felt threatened in a sexual nature. Sam, for example, described an

incident where he was potentially subjected to a sexual assault by another man. Sam was also aware that this kind of incident could happen again:

Sam*: It has happened to me in the past. It happened in the hospital and it's happened in real life. It can be very dangerous.*

In a similar vein, Letwin described an incident where he felt threatened by a man who was apparently targeting men with learning disabilities. These extracts also suggest that these men exhibited an awareness of sexual threats, which is counter to other research which has suggested that adults with learning disabilities are less knowledgeable about almost all aspects of sex and therefore appear more vulnerable to such abuse (Murphy and O'Callaghan, 2004):

Letwin: *Well the police wanted to interview me about a man who had been coming around befriending men with learning disabilities.*

Researcher*: When you say befriending, what do you mean?*

Letwin: *You know becoming friends for the wrong reasons.*

Alongside the extracts presented in Chapter Six, which demonstrated how men were exposed to different forms of harassment and victimisation, these accounts further reveal the interplay between disability and gendered power relations. In short, men who are perceived to lack the material or physical capacity to stand up for themselves may find that other men seek to exert power over them (Connell, 1995). Thus, these accounts have highlighted how this group of men are particularly vulnerable in certain 'masculine' environments, such as the pub. Those men who did drink in pubs all reported feelings of vulnerability associated with drinking too much alcohol. This included a fear of what they may be subject to while under the influence of alcohol. In these ways, their experience and perceptions confirm the value of a theoretical approach that encourages unravelling differential experiences of masculinity amongst men (Connell, 1987; 1995; Coles, 2009). The next section discusses this further in relation to how the men experienced and perceived health promoting behaviour.

Experiences and perceptions of masculinity and health promoting behaviour

The ways in which men demonstrate masculine identities have increasingly been linked with men's use of healthcare services (Moynihan, 1998), with men's emphasis on self-reliance and stoicism apparently resulting in the underutilisation of such services by men, compared to women (Galdas et al, 2005). In light of this evidence, the men were asked whether they thought men generally accessed healthcare when they had a health problem. Whilst

these men demonstrated a good awareness of their specific health problems and the importance of acting on health advice (see Chapter Six), they believed that other men were more ambivalent about health problems and seeking out advice from the doctor:

Alan*: Some men do, some men don't. ...Perhaps they just don't want to, just can't be bothered. They probably have fears of you know, testicular cancer.*

As is apparent in this extract, men often raised the issue of fear when discussing why they thought men generally found it difficult to get help from the doctors. The following account from Jack also mentions fear, though he reiterated the value of accessing healthcare:

Jack: *A lot of people do say that, but I don't. That men are frightened of doctors. What do you have to be frightened of doctors for? They're there to do their job. Looking after you, we'd be stuck without them.*

Most of the men interviewed perceived that it was important for them to take responsibility for their health and get health concerns dealt with. They also recognised that they were potentially different to other men in that they saw the value of seeking out professional help regarding their health:

William: *Because if they don't it's going to risk getting more damage on their own lives.*

George: *I just go to the doctors when they can book me in. ...I think they [men], should get it sorted out.*

Norris: *Yes, you should look after your health. I go to the doctors for almost everything. I think we should go to the doctors. If we don't we will be bad.*

Jack: *I always feel much better talking about it.*

In emphasising the importance of early consultation and reiterating that they were not frightened by seeking medical help, these men appear to be reworking certain masculine norms so that they are able to present themselves as 'real' men. This type of response is in keeping with other research (e.g. O'Brien et al, 2005), that has shown how men may redefine aspects of hegemonic masculinity when presenting a rationale for frequent use of healthcare, which otherwise may have assigned them to marginalised or subordinated positions in relation to other men.

As well as their frequent use of healthcare, these men also tended to

advocate personal responsibility regarding certain health related behaviours, such as alcohol consumption, which was often perceived as a potential hazard to health and a futile way in which to demonstrate masculinity:

Rob*: Well they should do. If they want to carry on killing themselves, let them carry on.*

Oliver: *Many men these days reckon if there're drinking it makes them a man. But if you're drinking it does not make you a man. If you're drinking too much, it just makes you out to be a piss head.*

In making these connections, these men were also keen to see themselves as different to other men. Oliver, for example, was very clear to differentiate himself from other men who he believed consumed too much alcohol:

Oliver*: I am not like some people, you know, who go out drinking loads for the fun of it.*

Oliver reflected a more responsible attitude towards alcohol, which he believed was necessary to avoid the negative health outcomes linked to heavy drinking (de Visser et al, 2007):

> **Oliver:** *At the end of the day I am not bothered about drinking. If they want to ruin their life that's their problem, not mine.*

Clearly, therefore, many perceived other men as less likely to adopt health promoting behaviour and, as such, they wanted to distinguish themselves from such behaviour, which are practices not usually associated with hegemonic ideals (Dolan, 2011). Similarly, those men who did drink tended to qualify the amounts they drank, which they often linked to issues of health and fitness:

> **Derek:** *Keeping fit is what I really want. ...I don't drink pints I drink halves.*

> **Norris:** *I'll have one bottle of Budweiser and then a coke. ...I don't like too much it gives me a bad head. Just stick to one bottle of Budweiser.*

Their desire to keep 'fit and healthy' also demonstrates how these men recognise certain masculine behaviours as potentially damaging, which echoes other studies where men recognise the necessity to keep healthy (e.g. Noone and Stephens, 2008). The desire to maintain health is also reflected in the following extract by Kevin, who used to smoke and who was aware of the health damaging effects associated with smoking:

Kevin: *I once smoked but my health comes before anything. ...When I was smoking I was getting out of breath, wheezing and coughing a lot. ...I feel much better now.*

It was also the case that a number of men demonstrated a good level of understanding regarding health concerns and were able to perceive the importance of taking action to monitor these conditions.

William: *You need to watch your own heart rate. ...And make sure the blood pressure does not get too high.*

Tom was also aware of the impact of hypertension:

Tom*: It puts pressure on your heart.*

These men also demonstrated an acute awareness of a number of specific health conditions:

Conner: *Well it has been on the news quite a bit, cancer, prostate cancer. ...And heart disease as well.*

Conner's father had died from a heart attack when he was young so he appeared very aware of men being more at risk of premature death from heart conditions:

> **Conner:** *Well my real dad died of heart attack when I was very young. ...He played a lot of Rugby, but still passed away.*

A number of the men also focused on male-specific conditions, particularly testicular cancer. They reported self-examining and the potential consequences of not checking on a regular basis:

> **Jack:** *Well I do, every week. ...I do it myself. A lot of people say women have pain down there, but you know men do as well.*

> **Letwin:** *Well you don't want to end up losing your nuts!*

Their accounts indicate a level of sensitivity and genuine concern for male health issues, which represent a departure from more dominant views regarding how men act in relation to their health (DH, 2008b). Moreover, the accounts suggest a heightened awareness of the adverse consequences of specific health issues that are left unattended. However, whilst these men appeared to have taken on board health promotion messages aimed at

men, there was also a sense that these men lacked knowledge regarding their health. Harry, for example, perceived the importance of self examination, but also admitted that he was not sure about how to do it:

Harry*: I do check myself over for that [testicular cancer], but I probably don't check as well as I should do, because I am not sure how to do it properly.*

However, Harry was aware of national men's health week and had used this as the impetus to make an appointment with his GP. Thus, he showed awareness of health promotion initiatives specifically aimed at men and was prepared to take action on the basis of that:

Harry*: I'd put myself in for a medical exam in June, which was national health man's week. I had to have a blood test and cholesterol test. They all came back perfectly normal, so I'm not diabetic.*

Harry also linked this concern to his age and recent changes in his health:

Harry: *Because I'm sort of knocking forty now you know, they recommended you should have a sort of MOT. ...I just wanted to know how I was doing. I do a lot of physical work. I kept finding I was getting a*

lot of pains in my chest. And I was concerned just worried. And if it was

high cholesterol or anything it would, you know, some warning of it.

Thus, in contrast to the dominant narrative which suggests that men are generally reluctant to seek help, regardless of their health concerns (Ridge et al, 2010), these men demonstrated a clear desire to access their GP and valued the importance of doing so. In line with other research in making sense of their behaviour these men presented themselves as 'knowledgeable' and 'legitimate' users of healthcare services (cf. Noone and Stephens, 2008; O'Brien et al, 2008). As disabled men, with specific intrinsic health conditions, they perceive the importance of acting on health concerns as a means of preventing the risk of their health deteriorating. In short, they appear to be a group of men who are willing to both listen to and act upon the health promotion messages aimed specifically at them.

Conclusion

This chapter has explored how the men experienced and perceived masculinity and its impact on their health. In doing so, it has shown how this group of men have the capacity to not only appreciate varied aspects of masculinity, but also engage in discussion regarding how masculinity is a factor which potentially affects their lives and health. In making these connections, their accounts reinforce certain aspects of dominant masculinity, such as the emphasis on men to be independent and in control. This also highlighted their sometimes vulnerable position as learning

disabled men, which prevented them from achieving hegemonic status and often assigned them to subordinated/marginalised positions in relation to other men. These men were also often keen to distance themselves from other dominant expressions of masculinity, particularly concerning health related behaviours, such as smoking and alcohol consumption, and were keen to promote regular access of health care services. Overall, these distinctions demonstrate how men with learning disabilities' conform to, or resist, gendered influences and the significance this has for their health, which presents a more contextualised picture of the lives of men with learning disabilities. Alongside the accounts examined in chapter six and seven, this provides rich understandings as to how social dimensions, associated with disability, relative poverty and gender, co-exist and impact on the psychological and physical health of men with learning disabilities.

Chapter Nine

Conclusions

Introduction

This thesis set out to explore how men with learning disabilities experienced and perceived how key social divisions, namely disability, relative poverty and gender, impacted on their health. It adopted a comprehensive understanding of health, which recognised how both physical and psycho-social factors impinge on health. This concluding chapter first recapitulates the key features of the theoretical framework that informed the thesis and provided the rationale for the research design. The main features of the methodology that prioritised the perspective of men with learning disabilities themselves are highlighted next. The chapter then sets out the significance of the key findings of the thesis in relation to existing research and concludes with the implications for the future development of policy, practice and research.

Theorising the impact of social divisions on health

The concept of social divisions relates to substantial material and socially constructed differences between people and offers a way of understanding experience of social conditions associated with social inequalities (Payne, 2006). It is acknowledged that social divisions encompass different dimensions. However, for the reasons set out below, the thesis selected the exploration of disability, relative poverty and gender as a framework to

enable a deeper understanding of the complex nature of the impact of social divisions, on the health of men with learning disabilities.

A review of the literature showed how the development of the disability rights perspective resulted in a shift away from the medical model of disability, to the social model of disability, which emphasised that societal barriers were imposed on people with impairments. For people with learning disabilities, evidence of discrimination has been highlighted in acute care and access to primary health care (DRC, 2006; Abraham and White, 2009). Increasing evidence of the victimisation of people with learning disabilities has revealed further examples of disabilism in the course of social life (Quarmby, 2011). The literature review revealed how within disability research there has been growing awareness of the impact of impairment alongside disability on the lives of disabled people (Hughes et al, 2005). However, these major theoretical debates have not been extended to include the voices of men with learning disabilities, while highly relevant in relation to their experience and perception of impairment and disability and its impact on their health. Neglect of this perspective has potentially adverse consequences for the health of this group of men and formed part of the rationale for gaining the standpoint of men with learning disabilities through the research.

In reviewing the literature on relative poverty on the health of men with learning disabilities, three factors were revealed that were influential in

establishing the second main focus of the study. Firstly, the literature showed substantial evidence that in the general population; socio-economic disadvantage is linked with poorer chances of both physical and psychological health. Secondly, it showed that people with less severe learning disabilities are more likely to live in socially disadvantaged circumstances. Thirdly, it suggested that living in such circumstances is likely to impact negatively on the health of people with learning disabilities. Specifically, the evidence suggested that the majority of people with learning disabilities have a reduced income, are more likely to be unemployed and have poorer mental health. While this evidence is growing, no literature could be identified that specifically explored how men with learning disabilities experience how their reduced socio-economic position impacts on their health, and their perspectives on this. This limitation of the literature indicated that it was important to explore how this group of men perceived and lived through relative poverty and its implications for their health.

Finally, the theoretical framework for the thesis was informed by a focus on gender. The literature reviewed showed how studies explaining the difference between men's and women's health have previously tended to concentrate on 'lifestyle' explanations (DH, 2008b). However, studies have begun to take more account of a gendered approach, in order to explain the reasons for the possible differences between men and women's behaviour and perspectives (Doyal, 2000 and Courtenay, 2011). This shift in understanding has been further influenced by the shift towards a more plural understanding of masculinities and the concept of *hegemonic masculinity*

(Connell and Messerschmidt, 2005). This concept portrays masculinity as a multi-faceted phenomenon, with different hierarchies existing amongst men (Connell, 1995). However, to date, literature on the topic of men with learning disabilities and masculinity has been very limited. No research has explored specifically how men with learning disabilities perceive and experience the multiple facets of masculinity, and its impact on their health. These issues provided the rationale for the third main focus of the study's exploration of how men with learning disabilities experience and perceive the impact of social divisions on their health.

The literature review as a whole highlighted the complex nature of the impact that certain social divisions have on the health of men with learning disabilities. Alongside this, the review revealed how the accounts of men with learning disabilities have been neglected within this context. This has resulted in a lack of more informed and nuanced understandings in relation to this topic, which the empirical study aimed to contribute to addressing.

Research design and methodology

The ontological underpinnings of the empirical study reflect an approach that values the experience and perceptions of this marginalised group of men (Swingewood, 2000 and Chappell, 2000). The existing state of knowledge within disability research shows how people with learning disabilities are increasingly being included in research on different topics (Walmsley and Johnson, 2003; Atkinson, 2005; McClimens, 2010). This

study was informed by a participatory approach (Northway, 2010), which fitted well with the aims of the research, as it was underpinned by the standpoint that viewed people with learning disabilities as experts on their own lives.

In this study, the men were involved as steering group members and as participants through semi-structured interviews. The steering group offered a number of advantages. Initially, prior to the fieldwork it provided their insights, guidance and feedback on key documentation, which made it more accessible, and therefore helped in gaining access to the participants. Further advantages of the steering group included the confirmation of some of the findings from the participants and suggesting ways to disseminate the research.

Contemporary inclusive research challenges the notion of concentrating on people with learning disabilities' 'deficits' and instead promotes awareness of their capabilities (Inglis and Swain, 2012). Participation in interviews was encouraged by adopting a number of strategies. These included additional time to 'tune in' to participants' different communication styles through a series of preliminary meetings. These aimed to assess the participant's capacity to understand the purpose of the research, establish their capacity to provide informed consent and to develop a rapport with them. Whilst the majority of men in the study benefited from accessible pictorial information, not all required this to process responses. It should not be assumed that

every participant will require pictorial information, in particular those with a mild to moderate learning disability. The study concurred with Walmsley and Johnson's (2003) viewpoint that an initial emphasis on encouraging verbal dialogue and responding to each participant on an individual basis, amounted to an 'inclusive' approach. Moreover, focusing on the men's capability, rather than deficits, while employing pictorial information, as required, opened up the opportunity for the men to show how they understood the key concepts of disability, relative poverty and masculinity. Being receptive to how each man communicated allowed me to recognise and be responsive to their understanding of these concepts.

Nevertheless, there were a number of limitations to the empirical study. The analysis was drawn from a relatively small sample of twenty white men with mild to moderate learning disabilities. The research therefore cannot seek to represent a cross-section of the views of all men with learning disabilities. The interviews were not only potentially co-constructed between the interviewer and participants; the male researcher identity may have also influenced what the men thought they should say in the presence of another man (Oliffe, 2009).

More research is needed to evaluate the most effective ways of including the views of people with learning disabilities in research studies. This study showed how useful their membership of a steering group is; and how this, together with preliminary meetings and semi-structured interviews,

supported as required with supplementary accessible forms of information, proved to be a valuable set of tools for opening up debates on complex topics affecting the lives of people with mild to moderate learning disabilities. Despite its small scale, the study raised a series of significant issues that could be explored in wider studies.

Key Findings

Impact of disability and impairment on health

The men's accounts of their experience and perceptions of primary and secondary care, and of life in the wider community supported the standpoint that both disability and impairment have a significant impact on their health as men with learning disabilities.

- Feedback from the men demonstrated awareness of the adverse consequences for their health, of physical and psychological health conditions, primarily associated with learning disabilities.

- The men reported positive experiences of primary health care, notably due to GP's advice specifically related to learning disability related disorders. However, they also reported instances of disabilist neglect of their health requirements, in primary and secondary care, echoing previous studies.

- Disabilist victimisation targeting people with learning disabilities in the community at large has been widely reported. The men's accounts of

their experience of this phenomenon, uncovered its insidious, adverse short and longer term effects on their physical and psychological health.

Notwithstanding the negative effects of disability and impairment on their health, the men's accounts also displayed a greater capacity for looking after their own health in certain respects, than presented in existing research. They revealed a willingness to take on health promotion advice, not highlighted in previous studies. Developing and maintaining relationships with others is recognised as important to psychological health. Compared to the focus in previous studies on people with learning disabilities' constrained opportunities and capacity for friendship, the men's narratives indicated that they possessed a stronger inclination and capacity for sustaining friendships. Alongside this, was some recognition on their part of the health benefits of such relationships.

Impact of relative poverty on health

The accounts of the men in the study revealed a varied and complex picture of how relative poverty impacted on their health.

- The men living in supported accommodation and/or with carers were protected from coping on a reduced income. However, their lack of financial autonomy echoes existing research, but also highlights the potential risks of this situation for their psychological and physical health.

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- The reports by the men living independently extend existing research, by bringing out the health consequences of grappling with the constraints of relative poverty, associated with their poorer socio-economic position. Going without basic items and being forced to go without food, as strategies to manage their lack of income, were accompanied by psychological stress for the men and pointed to potential long term physical health problems.

- Most men's accounts illustrated how their low income and adverse health effects were associated with the limited nature of their employment opportunities, characterised by low paid, part time, insecure, menial work. They also identified such working conditions as having negative effects on their psychological health.

- In contrast, some men were able to hold down employment over a prolonged period and attain job satisfaction. These accounts confirmed the value of appropriate local authority support for employment, as highlighted in existing research.

- Men's accounts added a further dimension to existing research which has identified them as tending to live in areas of social deprivation. They showed that men were caught up in threats to their physical safety and psychological well-being on a repeated basis, associated with living in socially deprived areas.

Impact of gender on health

The men's perceptions and experiences of gender reveal how they possess a sharp appreciation of the different forms masculinity can take, and how these can impact on their health. Their accounts of resistance to and vulnerability to norms of masculine behaviour, also illustrate how obtaining the viewpoint of men with learning disabilities, contributes to a nuanced understanding of masculinity and health.

- The men revealed an understanding of traditional concepts of masculinity, such as the role of provider within the family, not previously highlighted in research.

- The men's narratives showed an acute awareness of the negative health outcomes associated with conventional male behaviour, notably drinking to excess.

- The men also demonstrated awareness of specific male health disorders, and the necessity to seek help for them, which represented a departure from reported general tendencies regarding male health damaging behaviour and reluctance to access health care.

- The men also revealed situations detrimental to their health, where they were bullied, abused or dominated by other men, within and outside of their learning disability community, on the basis of their learning disability. These accounts confirm existing research highlighting the men's vulnerability in varied situations.

Interconnecting social divisions

As previously stated, the three social divisions of disability, relative poverty and gender were chosen as a means of understanding the impact of social inequality on the health of men with learning disability. However, whilst the men's perceptions and experiences of these divisions and how each impacted on their health have generally been presented as discrete categories, it is also important to note that aspects of these divisions could combine to have a significant and undermining effect on the men's health. For example, many of the men reported how disabilist views regarding their abilities placed significant limitations on their employment opportunities, which had implications for these men in terms of them being able to fulfil the role as 'provider' which they often associated with masculine status. Moreover, should they be in paid employment, these men were consigned to part time and low paid occupations that resulted in their relative poverty and, in turn, their accommodation in mainly deprived neighbourhoods. The men's accounts of physical and psychological threats and abuse further demonstrated the ways in which aspects of each of the three divisions could combine to damage men's health. In these instances, the disabilist threats and abuse these men experienced, which they often associated with living in more disadvantaged neighbourhoods, consigned men to lower status or subordinated/marginalised positions in relation to other men; i.e. unable to live up to certain masculine norms related to toughness and ability to defend oneself and one's family. The interrelationship between the three social divisions of disability, relative poverty and gender is demonstrated in Figure One, which seeks to capture some of the ways in which these divisions

impact on different aspects of men's lives and thereby damage the physical and psychological health of men with learning disabilities.

*Extending theoretical discussion and debate*

Within the field of disability studies, significant debate has taken place regarding the distinction between impairment and disability. This debate has demonstrated a clear tension between those who place emphasis on the impact of disabling barriers compared to those who highlight the need to also incorporate the significance of physical impairments. In terms of the findings from this thesis, the men's acute awareness of their physical conditions combined with the hate crime experienced by the men is one clear demonstration of how an understanding of both disability and impairment are required if we are to develop a deeper understanding the health of men with learning disabilities. In providing empirical evidence of these and other experiences, this thesis therefore extends this debate from the perspective of a previously neglected group of men.

There is a vast literature that documents the nature of inequalities in health. The evidence also suggests that men with mild learning disabilities are more likely to experience reduced employment opportunities, lower income and live in social deprived areas. However, whilst the literature on low income and people with learning disabilities is emerging, none of this debate takes account of the impact on health from the perspective of men with learning disabilities. Thus, the findings from this thesis extend understanding in the field of inequalities in health by demonstrating how this group of men

experience the hardship associated with relative poverty and reveals new insights into the negative impact social disadvantage has for the health of men with learning disabilities. This adds to the wider literature on health inequalities and further demonstrates the merits of exploring the narratives of a male population residing on the margins of society.

Masculinity is increasingly recognised as multi-faceted and context-dependent. Central to this shift in understanding has been the concept of hegemonic masculinity, which has also been influential within the social science literature as a means of better understanding patterns of male health. However, to date, the significance of gender for the health of men with learning disabilities has not featured within this field of research. Thus, the inclusion of the perceptions and experiences of these men in relation to masculinity and its impact on their health is a valuable addition to this growing body of literature.

Figure One   Interrelated social divisions

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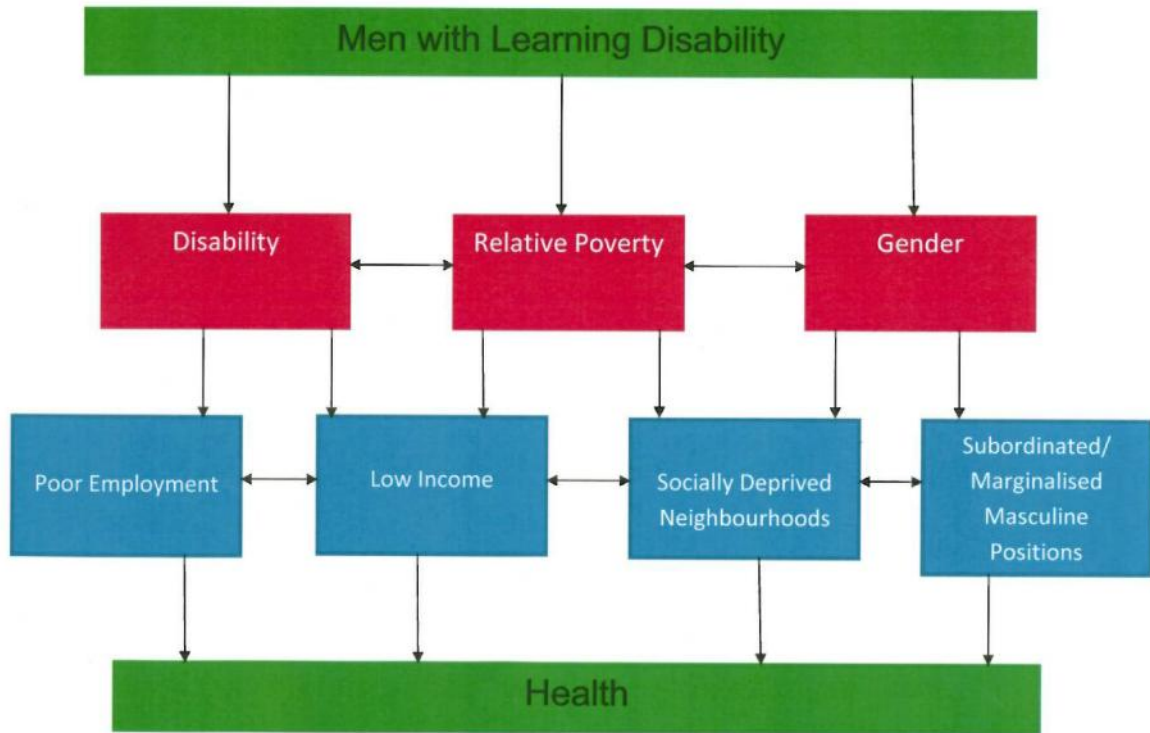
Implications for future research, policy and practice

Implications for research

Findings from this thesis, together with the outcomes of its methodology, highlight a number of specific areas in which further research would be beneficial.

Limited research exists that explores how people with learning disabilities experience the potential impact on their health, from living independently. A number of accounts portrayed the reality of hardship associated with relative poverty and its combined health damaging effects on an individual basis, amongst men with learning disabilities living independently. In a more extensive study, it would be beneficial to examine how widespread such conditions are, amongst people with learning disabilities. Obtaining such evidence on the extent and nature of the problem, could usefully contribute to analysis of the significance for health, of welfare benefits levels, and supportive employment opportunities.

This study has shown that when given the opportunity, men with mild to moderate learning disabilities have the capacity to understand complex issues - such as in this case, the impact on health, of different dimensions to social divisions, which up until recently would have been perceived as seemingly too complex for this population. This adds to other research that has validated the benefits of adopting a methodological approach that is responsive to the needs of this population.

The analysis of masculinity and health in general has not drawn on the experience of men with learning disabilities. This thesis suggests that men are capable of grasping key concepts on this topic, and by including their commentaries, contributes to a more nuanced and rounded account of masculinity and health. Future research could include a larger sample of men with learning disabilities, to establish a wider understanding of how masculinity impacts on their health and daily lives.

Initiatives to encourage GPs in providing health promotion interventions to learning disabled patients remain a contemporary issue (Houghton et al, 2012). Accounts from this study indicated that men with learning disabilities were willing and had the capacity to take on health promotion information, and that they also valued their GPs providing specific advice on learning disability related disorders. This suggests that it would be worth undertaking a more large scale action research study, to explore whether these findings could be replicated and fed back to GPs. This could encourage their continued targeted health promotion interventions with this group, on the grounds that such patients were receptive to them.

Implications for future policy and practice

A number of policy and practice implications can be drawn from the findings of this thesis. The research reflected the incidence of victimisation and disability hate crime that this group of men face and its adverse consequences for their health. Local safeguarding policies already exist that

aim to promote the safety of all vulnerable adults (DH, 2011). Drawing on the findings of this study, future policies need to encourage all health and social care practitioners to be vigilant to the negative physical and psychological health consequences associated with victimisation and hate crime, as a further dimension to their undermining effects on the well-being of these men.

A significant amount of evidence exists regarding socio-economic position and the health of the general population. This includes feedback from various groups, such as single mothers parenting in poverty (Graham, 1996), that provides first hand evidence of the impact of relative poverty on their health. Evidence is emerging that demonstrates that people with less severe learning disabilities are significantly more likely to be in poorer socio-economic positions and experience poverty (Chapman et al, 2008; Emerson et al, 2009). Being based on the men's own accounts, has enabled this study to illustrate graphically how reduced income, poorer employment opportunities and living in deprived neighbourhoods, confine them to the constraints of relative poverty and its adverse effects on their health. The Learning Disability Observatory, hosted by the Department of Health in England (Emerson and Baines, 2010) has begun to gather evidence on health inequalities and learning disability. This study endorses how a crucial dimension to developing a policy review examining the health consequences of poverty for people with learning disabilities, is inclusion of their own perspective on this.

Organisations overseeing the training and induction of generic health professionals have begun to involve this population in the design and delivery of induction training and men's health days (Personal Communication, 2013). The men's awareness of their own health conditions as learning disabled men, and of specific male health related disorders, adds weight to the potential benefit of such activities. Examples of specialist learning disability nursing practice do exist in the United Kingdom, which promote specific health promotion activities with people with learning disabilities (DH, 2012b). The men's alertness regarding health conditions endorses the benefits of pursuing these practice initiatives. Their readiness to take up health promotion measures also opens up the opportunity to employ the men as advisors on targeted health promotion events, to specialist organisations and relevant professional groups.

Conclusion

This thesis aimed to develop a deeper understanding of the impact on their health of certain social divisions as experienced and perceived by men with mild to moderate learning disabilities.

This has been achieved by grounding the research in a conceptual framework that addressed the significance of disability, relative poverty and gender, and informed by a participatory approach. The thesis produced

significant new findings in the following areas, with implications for future research, policy and practice. It uncovered nuanced insights into the significance that disability, together with impairment, has for the health of men with learning disabilities; into their capacity to understand and manage their health, and into what aspects of health care and wider social conditions can put it at risk of further deterioration. The research further revealed how the men perceived and grappled with the realities of relative poverty and its insidious effects on undermining their physical and psychological well-being. The men's accounts contributed as well, to a more informed understanding of masculinity and its impact on health. This included examples of the health benefits of men with learning disabilities' resistance to conventional gendered health behaviour. It also featured the men's vulnerability, as marginalised in relation to other men, which exposed them to health threatening violence and abuse. The composite impact on the health of men with learning disabilities, of all three social divisions also became apparent. These findings were produced by giving primacy to the viewpoints and experiences of men with learning disabilities themselves, which have significantly enriched knowledge and understanding of the topic.

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Appendix 1

Gatekeeper Letter for Steering Group

Martin Bollard

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Dear ...**, Re. Research with Men with Learning Disabilities; Health.**

I am writing to you regarding my PhD Research, which I am undertaking at the School of Health and Social Studies, University of Warwick. My research seeks to explore the lives of men with learning disabilities, with a focus on their experiences of Health Inequalities. I have worked in National Health Services for people with learning disabilities for over 15 years and I have undertaken a number of research projects in my capacity as Learning Disability Nurse and as a Senior Lecturer at Coventry University.

In order to promote active service user participation for my research, I would like to seek the help of three to four men with mild learning disabilities, to form a steering group, as the initial stage of my research.

The steering group will help me develop information leaflets, consent forms and areas of questioning for subsequent interviews with other men with mild learning disabilities, who do not attend your advocacy organisation. I anticipate meeting with the steering group volunteers on three occasions over a nine to ten month period. I would be grateful if you could recommend an appropriate place for the steering group and myself to meet up in.

I would like your assistance with identifying workers within your advocacy organisation, who could help me liaise with men with learning disabilities, who may then wish to volunteer to be part of the steering group. Once you have granted me permission to approach the workers, when I meet these workers, I will provide them with information sheets regarding the research.

I am happy to meet up if you require any further information regarding my research. I look forward to hearing from you. My telephone contact number is 07851 780628 and should you need it, my email address is martin.bollard@coventry.ac.uk.

Yours truly,

Martin Bollard

Appendix 2

Information Sheet for Steering Group

Research with men with learning disabilities; Health.

My name is Martin Bollard and I am doing my research at the University of Warwick. I need some help from men with learning disabilities with this research.

What is the aim of the project?

I want to find out what men think about their health and what affects it.

- What goes on in the lives of men with learning disabilities that affects their health?

- Do you think your learning disability affects your health?

- Do you think where you live and what you do during the day affects their health?

- Do you think being a man can affect your health?

- I am only interested in what you as men yourselves think.

How could you help?

- You could have important ideas that could help me design the research.

- As part of a small group of 3-4 men with learning disabilities, together you could help me think about important questions that I can then ask other men with learning disabilities.

- We will meet at least three times

How will I help?

- You can help me think of questions that I can then ask other men with learning disabilities about their health.

- I will bring some information about the research with me that we can discuss together.

- Once I have asked other men these questions, you can help me understand what their answers mean.

What's involved

- We can meet in the same place, each time and in a place where it is quiet.

- You can say no at any point

- You will not be put at risk.

- You can stop at any time you like.

- Your name and where you live will be kept confidential/ private. All the information will be kept securely

Martin Bollard

Appendix 3

Information Sheet for Interviewees

Men with learning disabilities and their health
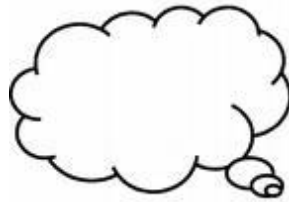

My name is Martin, and I am doing a research project at the University of Warwick.

The main aim of the research is to find out what men with learning disabilities think about their lives?

I am trying to find out what you think affects your health as a man with learning disabilities?

I want to know what you think about where you live and what you do during the day?

Your key worker will explain how you can become involved in the project.

We will be talking together for about an hour and a half in a room you know well or in your own home. We will have a break in the middle.

I will ask you questions, but you do not have to answer them if you do not want to.

Our interview will be recorded, but we can stop the interview at any time you like.

All the information we share and your personal details will be kept safe in a locked cupboard.

I am afraid I will not be able to pay you for the interview.

Thank you for taking the time to go through this information sheet. We can go through it again if you decide to volunteer.

Martin Bollard

Appendix 4
Consent Form

Men with learning disabilities and their health

[   ]

Interview Number

This form is so that you can tell me you are happy to take part.

Please put a ✓ **in the YES OR NO box to all questions and sign at the bottom.**

	YES	NO
I have read and understand the information sheet about my involvement in this research		
I understand it is my choice to take part and I can stop at any time		
I understand all the information I give will be kept safe and confidential		
I understand that the information I give may be used to share what men with learning disabilities think about their health		
I am happy for the interview to be recorded		
I want to take part in the interview		
Signature		

Appendix 5

Interview Schedule

Date

General Introduction and purpose of the interview

Number

Age

Ethnicity (prompt categories)

<div style="border:1px solid black; padding:10px;">

Accommodation Details

Where?

Who do you live with?

How many bedrooms?

Are you single/married/with a partner?

Post Code

</div>

1. Basic Information

I would like to ask you a bit more about where you live.

How long have you lived there?

What do you like about living there?

What don't you like about living there?

Are there people in the area you talked to?

Do you feel safe in the area?

Have you ever had problems with people in the area?

I would now like to ask you about work.

Do you have a job at the moment?

Is it a paid job or voluntary?

How long have you worked there?

What do you do at work?

Do you like where you work?

Would you like to work in a different place?

Is there anything about where you live or your work that gets you down, has made you feely poorly? Is there anyone you have been able to talk to about this?

I would now like to ask you some questions that will give me a general picture of your health.

2. **State of Health** (*I'd like to get a general picture/ idea about your health*)

Would you say your health was excellent, / good, / fair, / poor?

What makes you say that it is excellent, / good, / fair,/ poor?

How has it been in the past?

Can I ask whether you have any extra health issues? For example, hearing, sight, heart difficulties?

What sorts of things do you do to look after yourself?

Do you drink?
Do you smoke?

Experience of Health Care *(I'd like to ask you about going to the Doctors, treatment/ check ups?)*

How often do you see your doctor?

When you go to the doctor, do you go on your own?
Is he/she good at explaining things to you?

Do you feel they speak to you?

Do he/ she ever ask you how you are feeling?

Do you ever feel down when you are talking about your health?

Do you have any check-ups for anything?

Have you ever had to stay in hospital?

How did you feel about that?

Were there things that you liked about it?

Was there anything you didn't like about it?

3. Material Circumstances (I am now going to ask you questions about money, what you earn?)

Do you get your money from what you earn, or from benefits?

How would you say you are doing financially these days?

> Would you say that you are doing very well, doing quite well, getting by all right, not doing very well or finding it really hard?

> Why do you say that?

How much money do you get a week?

Are there things you feel most people can afford/ buy that you have to do without?
How do you feel about that?

> What would you like to be able to afford?

Break for 10 minutes

4. Social Networks (*The next questions will ask about what you think about having friends and socialising, 'going out' with people you have something in common with/ like*)

Do you have friends that you see?

> How often do you see them, (once a month, once a fortnight, once a week, more often?)

> What sorts of things do you do together?

> Do you think having those friends is good for you?

> What things stop you from going out?

> How does that make you feel?

> Who do you talk to if you have a worry?

> Do you talk to your friends?

What other things do you like doing during the day/ how would you describe an average/ normal day?

5. **Male Identity** *(For the next questions, I will be asking what kinds of things men do, the way in which men behave and their health)*

When you think of 'being a man' what does that mean to you?

What do you think is difficult/ or hard about being a man?

What kinds of things do you think men like doing?

What kinds of things do you like doing, any things you don't?

Can you tell me more about this?

Are there things that affect men's health?

Do you think these things affect your health? Can you tell me a bit about this?

Do you think men look after their health?

Some people say that men are not very good at 'going to the doctors'? Do you agree, or not? (if agrees) why do you think that is?

Have you ever not gone to the doctors when you perhaps should have?

Can you tell me more about this?

6. Any other issues

Are there any other things that we have not talked about, that you think make a difference to your health?

Appendix 6
Letter to Gatekeeper for participants

Martin Bollard
School of Health and Social Studies
University of Warwick
Coventry
CV4 7AL

Dear ...   **Re. Research on Men with Learning Disabilities; Health.**

I am writing to you regarding my PhD Research, which I am undertaking at the School of Health and Social Studies, University of Warwick. My research seeks to explore the lives of men with learning disabilities, with a focus on their experiences of Health Inequalities. I, Martin Bollard have worked in National Health Services for people with learning disabilities for over 15 years and I have undertaken a number of research projects in my capacity as Learning Disability Nurse and as a Senior Lecturer at Coventry University. This research is being supervised by Eileen Mcleod and Alan Dolan at the University of Warwick.

This research seeks to talk to men with mild/ moderate learning disabilities, through face to face interviews. As Acting Director for Adult Services, I am hoping you will grant me permission:

1. To access day services and work options across the locality
2. To approach workers, once you have been able to identify them, within these facilities, with a view to them identifying up-to twenty potential participants.

Once you have identified the workers, I will provide them with information regarding the aims of the research and the format the interviews will take. I am happy to provide you with this information and the consent forms to be used beforehand, if you require to see them.

I have spoken to and provided information to Simon Brake at the local governance committee regarding this research and he is happy for the research to proceed with your approval.

If you require any further information, do not hesitate to contact me on 07851 780628, or martin.bollard@coventry.ac.uk.

I look forward to hearing from you.

<div align="center">Yours truly</div>

<div align="center">Martin Bollard</div>

Appendix 7

Sample of flash cards used with participants

Disability

Relative Poverty

Appendix 8

Age and Living Arrangement

Name	Age	Living Arrangement
Alan	33	Lives independently
Brian	42	Lives with single mum
Conner	30	Lives independently (privately rents house)
Derek	42	Lives with mum and dad
Ewan	29	Lives independently
Fred	52	Lives independently
George	59	Supported living with 2 other men
Harry	38	Lives independently
Ivan	43	Lives with dad
Jack	47	Supported living home with 2 other people
Kevin	57	Married (lives with wife)
Letwin	45	Lives independently
Norris	70	Supported living with 5 other men
Mark	47	Supported living with 5 other men
Oliver	18	Lives with mum and younger sister
Pete	35	Lives independently
Rob	44	Lives with girlfriend and 8 year old daughter
Sam	49	Lives independently
Tom	33	Lives independently
William	32	Lives independently

Appendix 9

Self Health Rating Symbols

Excellent

Good

Fair

Poor

Appendix 10

Summary of Research Results for Steering Group

How men with learning disabilities think disability, poverty and gender can make a difference to health

Since we last met, I interviewed a couple of men to try out the questions we agreed I should ask.

All the 20 men I interviewed were interviewed either at home or in a work setting.

I met with all the men at least 2 times before interviewing them. The information sheet you helped me develop explained how the men would be involved and why I wanted to interview them.

The results from the research provide new information in different areas. The following is a summary of the main research results that have come after the interviews have been read and re- read a number of times.

Thank-you for helping me with the research, I hope you will share what we have found out together and be happy to be involved in any future research/ projects.

1. Main Results Disability related

Health

The men had a good awareness of their health and how they should look after themselves. When their learning disability was considered, they found their GP and primary health care teams were helpful.

This means it is worth providing health information to this group of men, as they will act on it.

Hate Crime

Sadly, a number of men experienced disability hate crime, inside and outside of their homes. The men told me this had an effect on their health in a bad way, even after they had moved home.

Friendships

Unlike other research, the men I interviewed were able to form friendships over a long period of time with both learning disabled and non- disabled men. They were also able to undertake different social activities. This was a positive result and they told me this improved their health.

2. Main Results Poverty Related

Money

Most of the men had very little money. Financial independence may be seen as a good thing by

governments, but when this means you have to live in relative poverty, the men said it negatively affects their health. Some men went without eating all day because they had very little money. Some men would look to help their neighbours to make sure they got a hot meal.

Work

Only one man had a full time paid job. Some men were happy not to work. Some men felt only having low paid work affected their health and others were aware they had to be careful that their benefits were not affected. Some men were able to hold down part time work for a number of years. Importantly, some men felt their health and how they felt about themselves was improved, by being in work.

Where I live makes a difference to my health

The men were able to identify that they lived in difficult areas. Some men talked about how they felt unsafe because of where they lived and how this had a negative effect on their health. They gave examples of where windows had been broken in their homes and young people had driven cars and motorbikes onto their property. This had affected their health, for example sent their blood pressure higher. In a good way, some men had learned how to stand up for themselves when faced with such situations.

3. Main Results Masculinity related

Being a protector/ provider for the family

No-one has ever asked men with learning disabilities how they understand masculinity and health. The men interviewed had a good appreciation of different things associated with being a man and how men showed their masculinity, such as providing and protecting your family when needed. The men were able to tell men how men behaved badly with their health and how they saw this as stupid. For these men, keeping fit and healthy was important as well as being respectful to women, which some men recognised other men did not always do.

Vulnerabilities

Some men were able to discuss how they had experienced abuse from other men and how this made a difference to their health. They described events where they had felt vulnerable and threatened by other men.

Men and health care

The men told me that they thought they were different to other men when it came to listening to advice from health professionals. They thought it was not only important to get help when you felt unwell, but also important to act on the information given.

Feedback

During our previous meetings, you asked me how I would share my research. I am planning a number of

publications in journals, an easy read format of the research for the local authority and other people with learning disabilities and some conference presentations both in this country and abroad.

Martin Bollard

Researcher

Appendix 11

Draft Letter to Organisation/ Gatekeepers for Feedback Event

Dear ...

As you are aware I have been involved in a research project involving a number of men with learning disabilities across the city for the past number of years. The steering group and I would like to disseminate some of the key findings to other men with learning disabilities, as part of an approach to raise awareness of the social disadvantage the men have shared with me from the research.

If you would be willing to help me arrange such an event, please contact me on the following number 02476 795886/ 07805 443617.

I look forward to working with you to arrange the event to enable us to learn from what the men have told me about their lives and how their individual circumstances have impacted on their health.

Yours Sincerely

Martin Bollard

Researcher

Appendix 12

Employment Status of Participants