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‘I count myself as normal’: An exploratory study of men with learning disabilities telling their stories about sexuality and sexual identity.

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A dissertation submitted for the degree of Doctor of Philosophy in Learning Disability

Tizard Centre,
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Canterbury.

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Key words:

sexuality; masculinity; social constructionism; historical treatment of women and men with a learning disability, interpretative phenomenological analysis; sense of self; community participation; autonomy; occupation; finances; socio-sexual education; socio-sexual knowledge; personal and intimate relationships; parenting; bullying and abuse.

Abstract:

The discussion of sexuality and its expression is commonplace. One only has to look in a newspaper or turn on one's television for evidence of this. It is also a topic of discussion amongst academics of various backgrounds. However, in relation to people with learning disabilities, such discussion is often framed in negative terms and is concerned with such things as abuse, HIV and sexually transmitted infection, 'unwanted' pregnancy and challenging sexual behaviour.

Whilst there has been considerable research into such phenomena as abuse, and the attitudes of carers to the expression of sexuality by women and men with learning disabilities, there is little published research into the question of how men and women with learning disabilities experience their sexuality or sexual identity.

This study sought to explore the way in which a group of men with learning disabilities in South Wales experienced their sexuality and sexual identity using a qualitative methodology, namely, Interpretative Phenomenological Analysis.

It found, *inter alia*, that despite the participants seeing themselves as sexual beings their opportunities for expressing their sexuality were often limited and controlled by others. It also found that the participants saw themselves more in terms of their differences with other men than their similarities. These and other findings of the study are discussed in relation to relevant literature.

The dissertation concludes by considering possibilities for future research and changes in policy and practice that may facilitate the appropriate expression of sexuality by men with learning disabilities.

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Contents:

Introduction:

Although the subject of sexuality has been discussed for many years, the last few years have seen it frequently discussed at a national level rather than solely amongst a select group of academics. This is evidenced by The National Assembly for Wales '*Strategic framework for promoting sexual health*', the Department of Health '*National health strategy for sexual health and HIV*', and the Royal College of Nursing document '*RCN Sexual health strategy.*' Additionally, there has been an increase in the number of publications on the issue (e.g. Battacharyya 2002; Charles 2002; Heath and White 2002).

Despite such a growth in the discussion of sexuality, my experience as a registered nurse for people with learning disabilities was that the expression of sexuality by women and men with learning disabilities was rarely condoned, yet alone facilitated, by many carers and service providers. Rather, the expression of sexuality was perceived as a risk, or danger and something to be avoided whenever possible, a phenomenon also noted by others (e.g. Thomas and Woods 2003). I wondered why this might be the case and what might be done to change this situation. I was aware of a considerable number of studies of the attitudes of carers towards the expression of sexuality by men and women with learning disabilities. However, I was also aware that other than a few notable exceptions discussed later in this dissertation there was a dearth of studies actually seeking to ascertain the experiences, attitudes and feelings of women and men with learning disabilities themselves as to sexuality.

Initially, I planned to undertake a two part study. The first part of this was to be a study of men's experiences, attitudes, feelings and knowledge in relation to sexuality. I then intended to use the participants' responses to shape an interview guide that I would use in an attempt to explore whether carers' views differed from those of the men they cared for (see appendix 3, Ethical Review Check-list). However, as time progressed I became concerned that to undertake a two part study would result in my being unable to give sufficient time and consideration to either question. I decided, instead that I would prefer to do less, more thoroughly (Silverman 2000), hence the study focuses on men with learning disabilities and not also on carers as originally considered. A further concern was that by studying carers, I might simply have reiterated previously recorded observations.

The dissertation commences by reviewing literature pertinent to the study. The review commences with broader questions such as those of the definitions of 'sexuality', and 'why its expression is considered important'. As it progresses, it narrows its focus, firstly to look at the historical treatment of men and women with learning disabilities and then at expressed attitudes towards the expression of sexuality of people with learning disabilities by a variety of relevant groups such as formal and informal carers. The final section of the literature review considers some of the possible reasons why the expression of sexuality by men with learning disabilities may not be facilitated.

The second part of the dissertation discusses the choice of methodology and the method by which the study was undertaken.

The third part of the dissertation is concerned with the results of the study and a discussion of those findings.

The fourth and concluding part of the dissertation considers recommendations for future policy, practice, and research.

It is only fairly recently that men and women with learning disabilities have been provided with opportunities to voice their own stories. Yet this study and others demonstrate that they do have a voice and stories to tell. Women and men with learning disabilities are often perceived as a distinct group and researchers and others concerns may be with their difference rather than similarity to the majority population. However, this study and others, such as those by Booth & Booth (1996), attempt to demonstrate how their lives are shaped by the wider society.

Whilst I have interpreted what the participants told me, in the course of the research undertaken and the writing up of this study, I sought to represent the participants as they represented themselves to me as recommended by Atkinson and Walmsley (1999) rather than in stereotypical ways. That is to say, I have sought to give a voice to a group of men who have been silent about their lives and experiences and who are invisible to the majority population as a result of their exclusion from everyday life.

Part One: Subject specific literature review

1:1 Introduction.

This part of the dissertation seeks to provide a review of published literature on the subject matter under consideration. The initial aim of this section is to use such literature in order to develop a hypothesis as to why the expression of sexuality by people with learning disabilities[1] is generally regarded negatively. It commences with a discussion about the meaning of sexuality and why the expression of sexuality is important to human beings. It then provides an overview of the theoretical perspective from which the subject matter has been approached. It also considers current perceptions of masculinity in order that such perceptions may later be compared with the way participants (men with learning disabilities) consider themselves. An account of the way in which people with learning disabilities have been treated by wider society throughout history until 1971 is then provided. Although this section does refer, where possible, specifically to attitudes towards the expression of their sexuality, it also considers attitudes toward people with learning disabilities generally. The next section of the literature review considers changes in attitudes towards people with learning disabilities from 1971 to present day. However, unlike the first section of the literature review, this section focuses almost exclusively on attitudes relating to the sexuality of people with learning disabilities. The literature review concludes with a discussion of reasons posited in the literature as to why the expression of sexuality by men with learning disabilities may not be facilitated or even condoned.

1:2 Sexuality – What is it and why is it important to be able to express it?

1.2.1 Sexuality a growing discourse

As a subject of scientific study, sexuality is relatively new, (Gagnon 1977; Nye 1999). That is not to say that there was no concern about sexual behaviour and sexual morality prior to the eighteenth century. Indeed, as authors such as Foucault (1984) and Nye (1999) discuss in considerable detail, both the Ancient Greeks and Romans discussed sexual activities in relation to such phenomena as

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[1] Throughout this dissertation, I shall generally use the term 'people with learning disabilities' to describe the subject group. Where I use other terms this will be in their historical context and they will be placed in quotation marks.

ethics, medicine and philosophy. Likewise, the Christian church considered and dictated on such matters. Rather, what is meant is that there was a change in the way in which sexuality was considered and discussed.

It is argued by Foucault (1979) that until the seventeenth century sexual behaviour was viewed as an acceptable subject for discussion and such discussion was wide-ranging. He states that in many ancient societies such as China, India, Japan, Rome and the Arabo-Moslem countries sex was discussed in relation to such things as pleasure, intensity, quality and duration. For them, sexuality was considered the erotic art whereby its 'truth' was drawn from the experience itself. He also argued (Foucault 1984) that whilst Ancient Greeks were concerned with sexuality from a medical perspective, this concern was not about pathology or the form of sexual acts. Rather the concern was about the quality of the acts and a desire to integrate sexual behaviour with their more general concerns with managing health and the body.

Foucault (1979) then argued that between the seventeenth and nineteenth centuries, general discourse about sexuality and sexual behaviours was repressed and came to fall solely under the jurisdiction of juridical and medical bodies. Such discourse was not concerned with the experience of sexuality generally, but with its impact on children, the mentally ill, criminals, homosexuals, the obsessed and perverts. He posited the view that whereas previously these people had, for the most part, been ignored, law and psychiatry forced them to, *"...step forward and...make the difficult confession of what they were"* (Foucault 1979, p. 39) (i.e. 'perverts'). He, (Foucault 1979) amongst others, then argued that having described this 'sub-race' of perverts science then sought to impose morality on them under the guise of medical normality. It did so by positing the view that those who deviated from this norm were hysterical, manic or mad and that if such evils were not treated they would be passed to future generations and would result in the death of humankind (Foucault 1979; Gagnon and Parker 1995).

Science was thus portrayed as having set itself up as the ultimate authority on sexual matters. As a result, sexual behaviours, other than intercourse for the purposes of procreation, became pathologised. The corollary of this was that sexual behaviour was secularised and science took over from the Church as the arbiter of morality (Gagnon 1977). Sexuality, in its modern sense can be seen to have been created through the psychiatrisation of sexual behaviour which deviated from that which was acceptable, namely vaginal intercourse for the purpose of procreation (Nye 1999).

Foucault's exposition of the history of sexuality has been criticised for a number of reasons, including: a failure to take into account the importance of gender (Seidler 1987); a lack of accuracy in the dating of the medicalisation of sexuality (Nye 1999) and for denying the importance of repression (Gagnon and Parker 1995). However, despite these and other criticisms, his work has had considerable influence on the development of modern thinking on sexuality (Weeks 1986; Butler 1999).

Although 'sexuality', as a topic of study, may be the result of the psychiatrisation of 'perverse' sexual behaviour, the study of sexuality since its conception has not been restricted to psychiatry. Rather, sexuality has been studied by a large number of disciplines all of which have sought to explain it (Gagnon and Parker 1995) and / or exert some control over its expression.

Given the fact that numerous disciplines have studied the subject over the last century and particularly in the last two decades since the emergence of HIV and AIDS (Gagnon and Parker 1995; Parker and Aggleton 1999), one would think that defining the subject would be straightforward. However, this is not the case.

Until recently, sexuality was viewed as a natural fact. This belief resulted from the work of people such as Freud, Havelock Ellis, Kinsey, and Masters and Johnson (Gagnon 1977). They sought to demystify sexual behaviour and, *inter alia*, demonstrate that numerous forms of sexual behaviour occur 'in nature' (Parker and Aggleton 1999). For the most part such researchers did not seek to explain the wide gamut of human sexuality but simply regarded it as a 'natural drive' or 'given fact' that was both universal and biologically determined (Jackson 1987; Vance 1999). Although these theories had some negative effects, such as that they appeared to provide justification for gender inequalities, they did serve to place the subject of sexuality back in the public domain. Moreover, their work is said to have assisted women in their struggle for access to abortion and birth control, to have led to a recognition that women's sexuality could be separated from reproduction and their ascribed role of being a wife and mother, and to have assisted in the recognition of sexual abuse (Caplan 1987; Vance 1999).

From the mid 1960s, writers from a wide variety of fields expressed the view that whilst biology provided the preconditions for sexuality, sexuality was not itself biological, a given fact nor based on sexual drives, but that it was a product of cultural, economic, political and social factors (Gagnon and Parker 1995).

While this generally appears to remain the consensus of opinion, since the advent of HIV there has been a resurgence of medical interest in sexuality. For example, the frequently referred to, second edition of John Bancroft's (1989) book *'Human sexuality and its problems'* has been re-printed each year since 1989. Despite the fact that the title suggests that the text would be broad in approach, the one hundred and forty-five page section that discusses the basis of human sexuality, devotes only eighteen of those pages to psychological processes which affect human sexuality. The remainder of the section is concerned with physiology and hormones. Medical interest in sexuality may well be appropriate, for example, when the only form of treatment open to an individual is the removal of a breast or testicle, it is important that the effects of the surgery be considered, in relation to such things as the person's body image and sexuality (Rutter 2000). Likewise, 'body work' is an important part of nursing (Twigg 2002). However, there is a danger that re-medicalisation of sexuality will result in it being pathologised, particularly if it is seen as coterminous with disease. The corollary of this being that the medical profession would once again be viewed as the leading authority on sexuality. As in the past, whilst such experts may explicitly frame their discussions in terms of health and disease their implicit concerns may be about gender, morality and social order (Vance 1999). Such concerns can result in widespread fears and anxieties arising as a result of moral panic (Weeks 1989) which in turn result in increased medical and legal intervention in the permissible expression of sexuality (Rubin 1999; Vance 1999).

1.2.2. Defining sexuality:

Despite having reviewed the literature concerned with the study of sexuality over the past century, albeit briefly, no adequate definition has, as yet, been forthcoming, it continues to be seen as mysterious and chameleon like (Weeks 1986). All we are presented with are suggestions as to what factors influence it.

There are a number of plausible reasons for this phenomenon, one of which being the fact that sexuality research is not a singular field but is undertaken by many disciplines (Victor 1980) and has been influenced by various campaigners from, for example, feminism (Gagnon and Parker 1995).

If one reviews the considerable amount of literature that has been produced over the last two decades on the subject of sexuality one rarely finds an attempt at definition. Rather, it generally appears to be taken for granted by authors that their readers understand the nature of sexuality (Vance 1999). Even where an author does provide a definition it is often only in vague terms. An example of this can be found in Aylott, (1999) who simply states that, *"...sexuality is part of being human. It is as individual as fingerprints"* (Aylott 1999, p. 442). Given such limited definitions and the fact that the term 'sexuality' covers such a broad range of topics it is little wonder that carers have difficulty in understanding what is meant by the term and may feel uncomfortable when advised that they should consider the subject when caring for clients (Carr 1995; RCN 2000).

If for no other reason that this dissertation is concerned with the subject of sexuality, it is important to provide the reader with some clarification as to what is meant by sexuality in the context of this study.

In seeking the meaning of a word, one place people commonly look is in a dictionary. Whilst there are some excellent and fuller discussions of the meaning of sexuality elsewhere, for example, Weeks (1986) these tend to be in specialist publications and are not necessarily readily accessible by the interested non-specialist. For this reason, I shall make use of a readily available dictionary, the Concise Oxford Dictionary (Thompson 1996). This provides two definitions of sexuality in relation to humankind;
"(i) of or relating to sex, or to the sexes or the relations between them, (ii) having a sex." 'Sex' itself has five meanings, namely, *"(i) either of the main divisions (male and female) into which living things are placed on the basis of their reproductive functions, (ii) the fact of belonging to one of these divisions, (iii) males or females collectively, (iv) sexual instincts, desires, etc., or their manifestation, (v) sexual intercourse"*.

The enquirer is thus presented with meanings concerned predominantly with biology, reproduction and behaviours. These definitions may provide a starting point for the person seeking the essence of sexuality. However, they are based on ideas of the late nineteenth and early twentieth-centuries and fail to take into account more recent thinking on the subject.

That is not to say that such views are no longer held. As noted earlier, Bancroft, (1989) whilst noting the contribution of the social sciences to our understanding of human sexuality, is critical of the emphasis of social and cultural factors over biological ones. Likewise, the judge in the case of R v Jenkins (unreported) (Murphy 2000; Winchester 2000a) saw sexuality in biological terms when he found that a women with severe learning disabilities had consented to sexual intercourse by '*submitting to her animal instincts*'. Moreover, hegemonic masculinity, a basis for the continuing oppression of women and sexual and racial minorities is based on biological arguments (Gagnon 1977; Kimmel 1997).

Other authors, although not stating that sexuality is a 'drive', consider it to be an essential part of the self (Brechin and Swain 1987)[Caplan, 1987a #217](Padgug 1999). Some authors go further than this and argue that sexuality is the means by which individuals define themselves (Caplan 1987; Carr 1991). It can be argued that this is a way in which people have been encouraged to act (Padgug 1999). For example a person who states 'I am Gay' or 'I am Lesbian' is making a political statement that is also about belonging to a group. However, they are also placing greater importance on their sexual identity than other identities they may have such as their biological sex, race, class or profession. Weeks, (1987; 1995) argues that placing one's sexuality above one's other identities is incorrect, as it suggests that one's identity is 'natural' or pre-ordained, when in reality our identities, including our sexual identities are a matter of choice rather than destiny.

Sexuality may not only be seen as a means of defining the individual, but also as a means of defining and delineating the world in which the individual exists (Weeks 1986; Padgug 1999). For many, sexuality is regarded as appertaining to the private sphere rather than the more public arenas of, for example, politics, employment and economics. There is some merit in the argument that sexuality should be a matter for the individual, in so far as where individuals are not harming others they should be allowed to do what they want, and it should not affect such things as their employment prospects or insurance cover. In fact, British criminal law asserts the claim, albeit fallaciously, (Wheeler 2003a) that in relation to sexual behaviour it does not interfere with private acts. This assertion can be seen in the Wolfenden Report (1957), the Criminal Law Revision Committee (CLRC) working paper (Criminal Law Revision Committee. 1980), the CLRC report (Criminal Law Revision Committee. 1984) and the Home Office review of sexual offences (Sexual Offences Review Team 2000). All of these argue that, other than providing protection from unwanted sexual acts, criminal law should not interfere with matters of private morality (Atkins and Hoggett 1984). Whilst this attitude has been largely realised in relation to the decriminalisation of homosexual acts, it appeared absent in relation to the criminal law relating to the sexuality of women and men with learning disabilities that was in force at the time of this study.

However, the fact of the matter is that most people do not behave in ways the law and others arguing that sexuality appertains to the private suggest. That is to say, people do not leave their sexuality at home. Rather, they take it with them into the wider society where it may affect many aspects of their behaviour.

If we deny this public nature of sexuality, we are in danger of returning to the outdated view that sexuality is innate and universal. Such a view results in it being more difficult to discuss the subject in a useful manner, for if sexuality is a private concern it is of no concern to others. This may then result in people's experiences being denied. For example, it was not until relatively recently that it was acknowledged that sexual abuse of people with learning disabilities and children was widespread and was taking place in a wide variety of situations. If one denies people their experiences public social action and change are then much harder to accomplish (Padgug 1999).

As stated above, in the last few decades there has been a move away from seeing sexuality solely in biological terms towards a view that it is, additionally, a social construct concerned with such things as learned behaviour (Gagnon 1977; Brown 1994). As a result of this change in perspective, the use of the term 'gender' was proposed and is now widely used. It is argued by Caplan (1987) that many people now see gender as being expressed through their sexuality and see each sex as having a specific sexuality. However, she argues that to do so denies a person a sexuality other than heterosexuality. That is to say although a person may be a man (sex) and have been socialised and developed into a male (gender or sex role) he may express his sexuality by loving another man. The fact that he loves another man neither changes his sex nor his gender. It is, therefore, important that we do not conflate sexuality and gender (Caplan 1987; Rubin 1999). However, Butler (1999) although agreeing that separating the two is crucial raises the question of whether in fact this is possible.

This having been said, most modern writers would argue that sexuality, although discussed as a specific subject, separate to things such as gender or reproduction can only exist in reference to the society in which it is embedded and to relationships, not only to ourselves, but to others and society (Caplan 1987; Jackson 1987; Weeks 1987; Padgug 1999). For example, Shepherd (1987) argues that in societies where there is a demand for children heterosexual intercourse is considered in a positive light essentially because it may result in offspring. In such societies, behaviours that prevent procreation such as anal or oral sex, masturbation and homosexuality are likely to be viewed negatively. On the other hand, she argues that in societies where the population is considered to be rising too quickly and there is a desire to reduce the birth rate, behaviours that reduce procreation will be considered more acceptable. Arguments such as these necessitate that we consider sexuality at both the macro and micro level in relation to such factors as culture, economics, politics and power relations (Moore and Rosenthal 1993; Davidson-Paine and Corbett 1995; Rubin 1999).

One starting point in the attempt to define sexuality is to enquire whether we are concerned with behaviour, a set of ideas, or both. If both, is there any relationship between them? If one looks at behaviour as the signifier in sexuality one is presented with a series of dichotomies, for example, male – female; heterosexual – homosexual; monogamous – promiscuous; married – unmarried. In each of these dichotomies one of the pairs is regarded as 'normal' and privileged, whilst the other is regarded as 'abnormal' or 'inferior' and is to a greater or lesser extent, disadvantaged (Caplan 1987). Acknowledgement of this phenomenon is important when considering power relations (Rubin 1999). However, sexual behaviours should not be considered the sole factor in identifying sexuality. That is to say, although specific behaviours may be universal, for example heterosexual or homosexual behaviour, heterosexual and homosexual identities are not merely located in the behaviour. For a man to have anal sex with another man (sexual behaviour) is one thing, but to be homosexual (sexuality) is another thing entirely (Thompson 1994) and is dependant on such multifarious factors as, class, gender, social position, politics and power (Padgug 1999).

That sexuality is bound up with power relations is a major theme in the writing of many authors. A classic example is the writing of Foucault (1979; 1984; 1984a). Weeks (1995) also emphasises the role of power in defining sexuality. In doing so, he notes that for women, those who transgress from the 'norm', i.e. heterosexual procreative sexual intercourse, and those who have been colonised either internally or externally, sexuality has been a prime means of finding one's self and one's identity. This is clear in the case of women and homosexuals and can be seen in the Women's and Gay movements of recent decades. However, due to the paucity of writing on the subject, it is less clear in the case of people with learning disabilities even though they clearly fall into the category of the 'colonised', many having been segregated and isolated as a group, both physically and conceptually, from the majority population (Weeks 1995). This being said, it has been argued that men and women with learning disabilities can and do use their sexuality as a means of asserting some control over their lives. For example, they may remove their clothes, masturbate publicly, self-injure or otherwise use their bodies as a 'weapon' in order to gain some control over their lives when forced to engage in an activity they dislike (McCarthy 1998). Such behaviour generally results in the individual being withdrawn from the disliked activity.

In answer to the question posited at the beginning of this section – 'What is sexuality?' one can state that it is a broad and complex concept (Daniluk 1998), covering a wide range of phenomena. Whilst concerned with, or based upon physiological or biological facts, to describe sexuality only in such terms is as inappropriate as trying to describe music solely by reference to a person's physiognomic auditory capability (Vance 1999). Likewise, to describe sexuality solely in terms of behaviour is insufficient, for whilst sex may be defined in terms of sexual behaviours sexuality is as much about ideas as behaviour (Foucault 1979). Moreover, although sexuality is at times appropriately described as being within the private sphere, it frequently crosses into the public sphere and both informs and is informed by the public sphere. In short sexuality is a complex area of life (Moore and Rosenthal 1993), which is an integral aspect of every human being (Sheerin and Sines 1999) and is a product of its historical, social and cultural setting (Weeks 1986). It is concerned with numerous aspects of life including: relations of power, sensuality, personal integrity, decision making, personal identity and self awareness, intimacy and relationships. To try to provide an acceptable definition that encompasses all these aspects is extremely difficult. This may be why so few writers even attempt to do so. Perhaps sexuality is best described through metaphor, one of the most satisfactory being that of Clifford Geertz's image of an onion (Geertz 1975) cited in Ross and Rapp (1997). Geertz suggests that as we peel off each layer, for example, economics, politics or power relations, we think that we are getting closer to the kernel or very essence of the subject. However, having removed all these layers we discover that there is no 'essence' other than the whole (Ross and Rapp 1997).

1.2.3. Sexuality's importance

Sexuality and sexual behaviour is important for numerous reasons. However, despite it being seen to be of considerable importance, it is only in recent decades that society has begun to voice its recognition of this (Gagnon 1977). This short section will consider a few of those reasons which may have particular relevance to men with learning disabilities.

The first reason of importance that will be considered is the fact that it is thought by many to be an essential part of the self. Victor (1980) posits the view that there are three dimensions of the self-concept, namely the biophysical dimension of existence, that is our experience of ourselves as a physical or biological being; the social dimension of existence, that is our experience of ourselves as an object of other peoples responses; and the personal dimension of existence, which is comprised of our reflections upon ourselves as a whole. Victor (1980) argues that the importance of sexuality in relation to our self-concept is that it cuts across all three dimensions. For example, in the biophysical dimension a person may have attitudes about such things as the way their body appears, how they experience masturbation, or menstruation as part of their bodily functioning. In the second dimension they may hold attitudes about their perceived attractiveness, masculinity or femininity or whether they are loveable. In the third dimension the person may feel positive or guilty about their sexuality and this may in turn affect their self-concept or self esteem. Although, Maslow (1954) does not argue that sexuality cuts across all dimensions of one's self concept, he does stress its importance. That is to say that he suggests that sex, love and belongingness are basic physical or psychological needs that must be satisfied before higher needs, those that promote the person's self actualisation, can be met.

Secondly, in addition to being a part of self, it is perceived as shaping the self. Weeks (1995) suggests that this is due to the fact that sexuality has been used by the state and the powerful (mainly white heterosexual men) as a means of exerting power over, and dominating women and the 'weak'. Such individuals have not always accepted domination willingly, and have instead, at times, responded by using their sexuality as a means of asserting power in their struggle for identity and self (Weeks 1986). Caplan (1987) also considers this idea, and the possibility that sexual revolution may not only result in personal liberation, but in social revolution. One example of how people with learning disabilities may assert control over a situation they dislike is to behave in an 'inappropriate sexual manner'. For example, if an individual doesn't like attending a day centre, they may start removing their clothing. Such behaviour is likely to result in their being withdrawn from the day service.

Finally, puberty and the physical changes that occur at this time signify to the child and the outside world that the person is making the transition from childhood to adulthood. Such changes are generally a cue for people to alter the way in which they perceive and treat the young person (Gagnon 1977). They may also result in development of the individual in relation to such things as increased independence and social competence (Moore and Rosenthal 1993).

Sexuality can thus be seen to be an important part of the self, and an essential component of the way in which one arrives at ones self-identity and the way in which you are perceived and treated by other members of society.

1.2.4. Men and Masculinity

1.2.4.a. Introduction:

Given that this study is concerned with the way in which men with learning disabilities experience their sexuality and sexual identity, an overview of literature considering current perceptions of men and masculinity is appropriate. This is in order that such perceptions can be compared with the way in which the participants consider themselves. This section will consider such questions as; 'What is a man?' 'Is there a masculine essence?' and 'What is masculinity?'

1.2.4.b. Defining and describing 'men' and 'masculinity':

The Concise Oxford English Dictionary (Pearsall 2002) provides the following definitions;

"Man *(n) - an adult human male"*

"Manful *(adj) - resolute or brave, especially in the face of adversity"*

"Manly *(adj) - having or denoting those good qualities traditionally associated with men, such as courage and strength"*

"Masculine *(adj) having qualities or appearance traditionally associated with men"*

These definitions may suggest a number of things. Firstly, that a man is a biological entity. Secondly, that certain personality traits or behaviours are associated with being male. Thirdly, the latter two definitions suggest that manliness and masculinity may not be fixed but may have changed and be changing (Shakespeare 1999).

Despite a considerable growth over the last three decades in the literature concerning masculinity, both academic and journalistic (Petersen 1998; Beynon 2002), one of the few things that appears to be agreed upon is that defining masculinity is difficult due to its fluidity and complexity (Collier 1995; Haywood and Ghaill 2003).

One of the reasons for this is that masculinity has been approached from a variety of viewpoints and disciplines, each emphasising or concerned with one aspect of masculinity over another.

For example, the subject of masculinity may be approached from a socio-biological, naturalistic perspective (Petersen 1998; Beynon 2002). In which case one may note, for example, that all men have penises, a similar chromosomal make up, and similar hormones. However, even these things may differ from man to man. For example, some men have higher testosterone levels than others and some men may have an extra X or Y sex chromosome. There is thus no single form of man. Despite this, some have argued that there is a male essence that lives or exists within the biological male and which is expressed through behaviour that is then considered natural (Whitehead 2002). For example, Darwinian, evolutionary explanations have been given for such behaviours as rape or infidelity. Likewise, men's violence towards others and their desire for power over (less powerful) others are seen as natural signifiers of masculinity (Whitehead 2002).

An opposing approach to the biological approach may be seen in that of sociologists of the 1950s such as Talcott Parsons. Parsons emphasised the importance, not of genetics but of 'sex-role socialisation' or 'sex-role theory' (Haywood and Ghaill 2003). Although sex-role theorists did not create the dichotomy of male v female, they sought to explain and justify it, arguing that the allocation of particular tasks to specific genders was necessary for the effective functioning of society (Whitehead 2002).

Such ideas are now generally considered untenable (Beynon 2002). Rather, it is generally accepted that whilst (wo)men are a biological entity they are also socially constructed. That is to say, that whilst one may be born with a certain genetic make-up, this does not necessarily mean our destiny is determined as a result of this (Whitehead 2002). For example, a person may be born to a family with a history of heart disease. However, this does not mean that s/he will die of heart disease. Rather, there may simply be a pre-disposition to such disease. The person's destiny is as much to do with their environment and lifestyle as it is their genetic make-up. Similarly, simply because one is born a biological male does not mean that one will express or experience one's masculinity in the same way as other males.

Alternative approaches to masculinity have also been presented by psychoanalysts such as Freud and Jung. Although Freud did not specifically write about 'masculinity', he did write about 'normal' male development. He suggested that whilst children were initially polymorphously perverse or bisexual their sexual instinct was normally shaped by their identification with their same sex parent. This necessitated them suppressing opposite sex desires or traits. Therefore in order to become a masculine adult male, the young male has to suppress 'weakness', homosexuality and emotion (Osborne 1993). Freud may thus be seen to suggest that both biology and socialisation have a role to play in the creation of masculinity and femininity (Whitehead 2002).

Yet additional approaches to masculinity have been presented by, for example; feminists (see Whitehead 2002), pro feminists (see Pease 2000) and legal theorists (see Collier 1995). Despite such a variety of approaches, it is argued by Peterson (1998) that insufficient attention has been paid to questions of epistemology and that there is a need for critical interdisciplinary enquiry.

If one considers masculinity through different theoretical standpoints and across different times, cultures and places, one has little choice but to acknowledge that rather than there being one definitive or objective form of masculinity, there are any number of 'masculinities'. Such masculinities are shaped by a wide variety of factors including ethnicity, class, culture, religion, age, and sexuality (Petersen 1998; Pease 2000). Masculinity is not, therefore, a simple self-construct, but instead is a social construct.

Masculinities are powerful and appear to exist in relation to femininity or femininities (Lees 1997). That is to say, that whilst in some senses masculinity may be illusory the consequences of masculinities, such as are seen in the everyday practices of men and the effects of powerful myths concerning gender do have real consequence. For example, they justify or sanction the dominant role of white heterosexual men within a variety of areas such as employment, poverty, and crime (Collier 1995; Whitehead 2002).

1.2.4.c. Past perceptions of idealised masculinity:

Although it is arguable that there is no definitive form of masculinity, there have previously been Anglo-Welsh 'ideal' versions of masculinity. Whitehead (2002) considers what it meant to be masculine in Anglo-Welsh society at a variety of points in history. For example, he notes that in the sixteenth Century men such as King Henry VIII, who were symbolic of English nationhood, were not only a complicated blend of ruthlessness and brutality but also of overt emotions. However, by the Victorian and Edwardian eras, an 'ideal' version of masculinity had emerged due to such things as Darwinism and the Protestant work ethic. In this idealised version of masculinity, manliness was portrayed in terms of such attributes as physical strength, courage, dexterity, stoical endurance, virility, intelligence and denial (of a variety of things such as emotions and luxuries) (Petersen 1998; Shakespeare 1999). More recently, particularly from the 1950s, masculinity has been portrayed in terms of men being rational, independent, in control, unemotional, competitive, distant from the family, and predominantly focused on work (Tepper 1999) and personal achievement (Seidler 1997; Beynon 2002).

1.2.4.d. A crisis of masculinity?

Recently, it has widely been suggested that masculinity is in crisis (Collier 1995; Haywood and Ghaill 2003). The argument is posited that as a result of a variety of changes in such areas as; employment practices; in changes to family and other law resulting in women and children no longer being seen as chattels or the property of men; and elsewhere in society such as the (qualified) success of feminism and the rise of consumerism, men are in a crisis (Collier 1995). That is to say, they are perceived to be uncertain about just what it means to be a man as they no longer have a clearly defined ideal role (Seidler 1997; Petersen 1998). For example, on the one hand, they are expected to 'take control' or 'be at the helm', on the other, they are expected to be reflexive and physically contribute to the running of the household by egalitarian co-parenting. Additionally they have been pathologised, or subject to numerous criticisms. For example, they are seen to be failing in education; to be violent; to suffer unnecessarily poor health (Watson 1998); to be more vulnerable to criminality and superfluous to reproduction (Seidler 1997; Haywood and Ghaill 2003). What is required, so the argument goes, is that men re-define themselves in order to prevent social order being disrupted.

Whitehead (2002) argues that if there is such a thing as a crisis of masculinity, it exists only in relation to white heterosexual masculinity where factors such as class, ethnicity, sexuality and disability are ignored. He, like Peterson (1998) and Beynon (2002) further posits the view that if indeed there is such a crisis within

Western masculinity, that crisis has existed for over half a century, it being present during the Depression of the 1930s as a result of many men becoming unemployed and losing their role as the 'bread-winner'.

Whitehead (2002) then goes on to consider a number of forms of masculinity such as Black, Latino and Gay masculinities and suggests that these exist in relationship, albeit marginalised, to white heterosexual masculinity. He further argues that such phenomena as the feminist movement, the gay liberation movement and queer theory have come about in response to the ideal of white heterosexual masculinity in,
"...an attempt to release individuals from the constraints of both biological determinism and the dualistic thinking that provides the very basis of (contra)identities such as black/white, woman/man, gay/straight." (Whitehead 2002 p.4.).

1.2.4.e. Masculinity today?

One of the changes that has taken place over the last two to three decades is the fact that men's bodies are now discussed much more publicly. It is arguable that the male body is becoming as much an object of consumption as the female body has been. For example, men's magazines, such as *Men's Health*, promote an idealised vision of masculine bodies and offer a variety of ways in which such an ideal may be achieved, for example through the use of cosmetic surgery, exercise, and various implements, potions and lotions. This phenomenon has been connected with the alleged crisis in masculinity by some writers who argue that the pursuit of the 'ideal' muscled body is the only remaining way open for men to demonstrate their masculinity (Haywood and Ghaill 2003).

Given this, it appears that the dominant masculinity that exists today, predominantly amongst white European heterosexual males, is one concerned with physicality. That is to say, the 'ideal' male is perceived to be physically competent, 'tough', or 'hard', thereby using his body to prove his masculinity, be this on the football pitch, in the gym or in battle (Seidler 1997; Haywood and Ghaill 2003). Some writers suggest that in addition to physical strength, today's 'ideal' male is also concerned with the placing of his physicality. That is too say, that the 'ideal' male is seen to occupy space in a way that demonstrates confidence, intentionality and purposefulness. This is said to be demonstrated by the way in which boys play. For example, they are seen to create space for themselves whilst restricting the space left for others, such as girls (Whitehead 2002). It is also said to be demonstrated by the way in which the male is expected to pacify his environment rather than be pacified by it. This can be seen in the way in which men seek to prove their masculinity by undertaking 'extreme sports' such as diving, mountaineering or parascending (Beynon 2002).

This dominant form of masculinity is seen to set the terms for the relationships of power between men and women. At the same time, however, a number of other masculinities exist that may challenge the power of idealised masculinity (Seidler 1997; Petersen 1998). Such masculinities include black, gay, and older men's masculinities (Whitehead 2002).

1.2.4.f. Concluding remarks on masculinity;

One is thus presented, not with a singular definitive version of masculinity, but with a range of masculinities that are produced through the complicated interactions of a variety of social and cultural factors. However, whilst there is such a range of masculinities, there is no doubt that one masculinity, that of the 'ideal', white, heterosexual male, is more powerful than other forms of masculinity and than femininities. To what extent, if any, men with learning disabilities either fit in with the 'ideal' or seek to emulate it is a question that it is hoped this study will go some way toward answering.

1:3 Public perceptions, expressed attitudes and treatment of people with learning disabilities - A historical overview

1.3.1 Introduction:

The history of the way in which people with learning disabilities have been viewed or perceived over time is instructive in that it provides the reader with insight into the development of attitudes towards people with learning disabilities, demonstrates fluidity of thought within society, and that society's attitude toward people with learning disabilities is capable of change. The latter aspect is of particular importance here given that one of the aims of this research is to develop guidance as to how the expression of sexuality by people with learning disabilities may be better facilitated. Additionally as Silverman (2000:p.84) notes, reviewing historical evidence enables one to ascertain how one's research problem came into being.

The section seeks to consider society's attitudes throughout history by looking at the way in which people with learning disabilities have been perceived and have been treated in the past. The main focus of this section is on the period from the nineteenth century to 1971, the time at which, it is suggested that the current thought on the care and treatment of people with learning disabilities began to develop in England and Wales.[2] This is due to two main reasons; firstly, there is a paucity of secondary sources relating to the period prior to the nineteenth century. Secondly, there was little recognition of, or interest in, learning disability as a specific and separate concept, as opposed to part of 'madness' prior to this time (Kanner 1964; Morris 1969; Walmsley, Atkinson et al. 1999, p. 187). A third view is posited by Goodey (1996) who suggests that their history has not been written because they were perceived as being sub-human or like animals and thus not worthy of writing about. Whilst secondary sources are the predominant source of this section some primary sources such as Hansard are used. Such sources assist one in understanding why particular legislation aimed at people with learning disabilities was introduced to the statute books.

Whilst the emphasis of this section is placed on British history, much of the writing on the subject is American. Moreover, many of the events described in this section were not isolated to England and Wales, but were part of a wider movement both throughout Europe and in North America. Where events occurred in countries other than the United Kingdom and these had bearing on practices within England and Wales, they will also be included in this review.

1.3.2 Pre 1800:

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[2] Law in Scotland and Northern Ireland frequently differs to that in England and Wales. This dissertation concentrates on the latter two countries.

There is little written about the treatment of people with learning disabilities in the period prior to 1800, however, a number of texts provide the reader with a brief 'historical background'. For example, Gilbert (1985) notes that people with learning disabilities and mental health problems had their property protected and were either treated kindly or left to their own devices in the "Judaeo-Hellenistic world". She suggests that popular beliefs in mediaeval Europe (5th -15th C) resulted in people with learning disabilities having a protected status, referring to the beliefs in 'changelings'. That is to say that people believed that their child had been substituted for a 'changeling' in the night by fairies or the like. In order to ensure that the fairies cared for their child, they in turn cared for the 'changeling'. She further notes that Christian writings of the sixteenth century viewed people with learning disabilities as being close to God, a view also subscribed to by Wolfensberger (1975). He argues that whilst considered to be 'children of God', people with learning disabilities were considered harmless and may either have been indulged like children or valued by their families and communities. However, Gilbert then notes that this perception of people with learning disabilities as being 'children of God' changed as a result of the Reformation of the sixteenth-century and the growth of Protestantism, in particular Calvinism, the adherents of which saw individual success as the means to salvation. Thus people with disabilities came to be seen as the result of their parent's 'sin'.

Likewise, Heaton-Ward (1977) also provides the reader with a brief history of the "development of care of the mentally subnormal". He notes, like Gilbert (1985), that attitudes have varied from time to time and place to place, with people with learning disabilities being, "*...alternately reviled and revered*" (Heaton-Ward 1977, p.46). He also provides examples, including the attitudes of the Spartans, who believed that people with learning disabilities were "cursed by the Gods". As a result of this belief they were allowed to perish or were drowned. He states this was due to the Spartan's concern to maintain the race. Like Gilbert, he states that early Christians had a more positive attitude to those with learning disabilities, but further states that such sympathetic attitudes were not confined to Christians but were also encouraged in the Koran and in the writings of Confucius and Zoraster. As with Gilbert, he notes that this 'positive' or at least 'neutral' attitude changed at the time of the Reformation and notes that Protestant leaders such as Calvin denounced people with learning disabilities as being, "filled with Satan". He further reports that Martin Luther referred to them as being, "*... illegitimate children* *of the Devil*" and actually went so far as to recommend that, "*...an imbecile boy of twelve be drowned*" (Heaton-Ward 1977: p.47).

Kathleen Jones (1972) also provides her readers with a brief historical background into the care of people with learning disabilities and mental health problems prior to the early beginnings of the 'Reform Movement' in the mid-eighteenth century. Similarly to Gilbert and Heaton-Ward, she notes that during the Middle Ages the harmless 'lunatic' or 'idiot' was generally treated with respect, but that this changed with the advent of the Reformation and the, "*...orgy of witch-hunting*" (Jones 1972: p.4). She further suggests that whilst penal laws against witchcraft were removed from the statute books in 1736, people with mental health problems and learning disabilities continued to be treated harshly by the 'uneducated' who continued to hold the belief that harsh treatment would drive, "*... the devil out of the lunatic*" (Jones 1972: p.5). She notes that even medical texts such as Burton's, *The Anatomy of Melancholy*, published between 1621 and 1821 saw 'mental and moral defect' as being the result of 'the fall of man' and recommended treatments such as purges and vomits, blood-letting and trepanation. She suggests that such thinking was influenced by theological thinking of the period which saw all forms of "human misery" as resulting from personal sin and the belief that, "*... the poor, sick and insane deserved their fate*" (Jones 1972: p.8). She posits the view that this theological thinking enabled the more fortunate members of society to accept such phenomena unreservedly. She acknowledges that religion was not the sole guide to human behaviour during this time, but suggests that philosophy tended to ignore the mentally disordered.

Kanner in his "*History of the care and study of the mentally retarded*" (1964) also provides a brief outline of the care of people with learning disabilities prior to the nineteenth-century. He, like Heaton-Ward, notes that there is reference to such persons in texts such as the Bible, the Talmud and the Koran. However, he suggests that reference to such texts is of little value other than to demonstrate that such people existed and that, "*...occasionally friendliness was (advocated) toward them*" (Kanner 1964: p.3). He then goes on to state that although some households used people with learning disabilities as 'fools' or 'jesters' the vast majority of people with learning disabilities were, until the time of the Reformation, regarded as 'children of God' and allowed to roam freely. He, like the writers previously discussed, then notes that the apathy that had been extant until the time of the Reformation was replaced with a negative view, whereby such individuals were seen as, at very least, 'Godless' and were 'demonised'. Additionally, Kanner notes the lack of reference to 'idiocy' in medical literature prior to the end of the eighteenth-century.

Unlike the previously considered writers, O'Conner and Tizard (1956) in their chapter entitled *'Historical Background'*, make only vague reference to the care of people with learning disabilities prior to the mid-eighteenth century other than referring to the legislation of Edward II (see below). Rather, their history commences with the work of Pereire (1715-1780).

Likewise, Parry-Jones (1972) provides little information relating to the period prior to the nineteenth-century. He notes the legislation of Edward II and also makes reference to the 1602 Elizabethan Poor Law Act, but posits the view that such legislation focused more on the poor and unemployed and asserts that until the late seventeenth-century,
"*...harmless lunatics and idiots continued to be left at liberty as long as they were not considered to be dangerous...*" (Parry-Jones 1972: pp.6-7).

In England, as noted above, there was legal recognition of the difference between those people with a learning disability and those with mental health problems as early as 1324 (Morris 1969; Heaton-Ward 1977; Gilbert 1985). This is evidenced by legislation passed at this time. The *Statute de Praerogativa Regis*[3] appears predominantly to be concerned with property matters. It distinguishes between 'idiots' or 'natural fools' and 'lunatics' and provides that the property of 'lunatics' should be preserved intact (other than expenses used for their maintenance) and returned to them on their recovery. Likewise, the property of 'idiots' (other than that spent on their maintenance) was to be entrusted into the custody of the Crown. On the death of the 'idiot' the property was to be passed to the 'idiots' heirs. Thus we see that the concepts of state responsibility for the care of the person with learning disabilities and guardianship are not wholly modern (Morris 1969; Neugebauer 1996). This statute would, however, have had little impact on persons without a valuable estate (Scheerenberger 1983).

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[3] 17 Edw. II. The statute is believed to date from an earlier period than this, but this is the first printed record of it.

Despite such an early recognition of the phenomenon of 'idiocy' by Law, most people with a learning disability were treated in the same manner as other indigent persons. They were essentially seen as a family problem and were cared for by the family. It was only if the family could not cope that people with a learning disability would be 'boarded out' or placed in institutions such as workhouses (Parry-Jones 1972), madhouses, various charitable institutions for the sick and in prisons (Morris 1969; Scull 1993; Rushton 1996; Wright and Digby 1996). It is partly due to this fact that people with learning disabilities remain essentially invisible in historical sources such as parish records (Andrews 1996).

In Scotland, the treatment of people with learning disabilities during this period is even less clear, as there is very little published work on the subject. However, Houston (1999) suggests that until the nineteenth-century 'idiots', 'imbeciles' and 'mad people' were found in a variety of situations, including in the care of their families, 'boarded out' with other families, in workhouses, hospitals and jails. Others were left to their own devices, to 'wander at large'. He does, however, note one major difference in the type of care offered to those the family could not cope with. That is he suggests that the use of doctors and clergy as carers for the 'better off' learning disabled and mentally ill was less common in Scotland than has been reported to be the case in England by writers such as Parry-Jones (Parry-Jones 1972). In fact, he goes so far as to state that,

"*...mad and idiotic Scots were almost always cared for by lay men and women who had no professional qualification (or pretension)*" (Houston 1999: pp.38-9).

As in England and Wales, there was legal recognition of the difference between 'idiots' and 'lunatics'. However, it would appear from Houston's research (1999) that the law and its process of 'cognisance' was used infrequently, in that he states that between 1701 and 1818 only 164 individuals became the subject of 'tutories' or 'curatories' under the law (Houston 1999: pp.19-20).

The most comprehensive 'history' of people with learning disabilities for this period would appear to be that by Scheerenberger (1983). He commences his work by considering the attitudes of the ancient peoples of Egypt, Sparta, Athens and Rome and notes that people were aware of learning disability, and described such phenomena as microcephaly. He states that treatment received by people with learning disabilities was variable, but this was essentially dependent on economics, that is to say that during times of poverty, anyone seen to be a liability would be treated harshly. However, he notes that at the 'end of antiquity' which he places at AD 476 the life of a person with a learning disability would be much the same as any other person of similar class, or parentage (Scheerenberger 1983: p.20). He then refers to the period A.D. 476-1799. He notes nothing, however, until the sixteenth century when he states that a number of physicians showed an interest in learning disability, but that the treatment of people with learning disabilities varied from place to place. Like other writers, he suggests that the Inquisition and its correlates, like the Reformation, resulted in negative and harsh attitudes being expressed towards people with learning disabilities. However, he suggests that as a result of an agrarian economy and the requirement for agricultural labour many people with learning disabilities would work in the fields along with the remainder of their family. He also notes that learning disability was distinguished from mental illness by law in 1324 and notes that as a result of this recognition attempts to assess intelligence were made as early as in the 1530s. However, he states that whilst great advances were made in general medicine during the seventeenth and eighteenth centuries progress was less rapid in relation to learning disabilities. He notes that the question of heredity was raised and that additional clinical forms of learning disability such as 'cretinism' were recognised. Despite this 'progress', he suggests that, in general, people not only considered that little could be done for the 'idiot', but also that they were seen to be less than human and unable to sense such things as heat, cold, hunger and pain. This perception of the learning disabled and mentally ill as being 'sub-human' or like 'wild beasts' is also referred to by Scull (1989) who argues that this perception justified their forcible treatment. As will be seen in a later section of this literature review, the comparison of people with learning disabilities to wild animals was not restricted to this period (Wolfensberger 1975). Like most of the other writers considered above, Scheerenberger (1983) sees the turning point in the care and treatment of people with learning disabilities as being in the nineteenth-century.

1.3.3 1800 – 1890: The movement towards universal education:

Greater professional interest in people with learning disabilities commenced in Europe with the work of individuals such as Pereira, Jean-Marc Itard and Edouard Seguin. Jacob Rodrigues Pereira (1715-1780), a physician, who was presented before King Louis XV as a result of his work with deaf-mutes, taught such individuals to read, speak, and undertake addition (Kanner 1964; Heaton-Ward 1977; Switzky, Dudzinski et al. 1988). He is also stated to have been the inspiration for the more famous Itard (Switzky, Dudzinski et al. 1988).

Itard (1774-1838), best known for his work with Victor, the 'wild boy of Aveyron', which commenced in 1799, devised a systematic educational programme with the intention of developing the cognitive abilities of people with learning disabilities in order that they might be returned to their communities as useful members of society. This system of education, sometimes referred to as 'sensationalism' was based on the belief that ideas were directly derived from the senses and that by stimulating the senses, a person would develop or produce ideas (Kanner 1964).

Despite the acknowledgement of the work of Itard which commenced in 1799, and the fact that the first institute for the education and training of people with learning disabilities had been established in Paris in 1928 (Jones 1960), most writers suggest that it was not until the mid nineteenth-century that concern for people with learning disabilities began to be expressed on a wider scale by educationalists, physicians and philanthropists (Adams 1971).

One of the leading workers in the field at this time was Seguin (1812-1880), a physician and a pupil of Itard's. He believed that education was the right of all children and developed a physiological method of education, which demonstrated that children with learning disabilities could benefit from education (Scheerenberger 1983). Seguin, although basing his work at the Paris Hospital for Incurables and at the Bicetre on that of Periere and Itard did not stress the role of the senses in educating people with learning disabilities, but rather, the role of physiological methods. Like other early workers in the field, Seguin initially believed that people with learning disabilities, once trained, would be returned to their communities where they would be able to hold down an occupation (Heaton-Ward 1977).

A contemporary of Seguin, Johann Jakob Guggenbuhl (1816-1863), another physician, also had a strong influence on the care, treatment and education of people with learning disabilities both in the United States and the United Kingdom. He founded the first segregated residential institution for 'cretins' in 1841 in

Switzerland. This 'colony' was visited by people interested in the care and education of people with learning disabilities from the United States and elsewhere in Europe and served as an inspiration for similar projects in America and England. However, the colony fell into disrepute and was closed down by the Swiss authorities following an enquiry into the conditions of the colony in 1858 (Kanner 1964; Heaton-Ward 1977).

A third individual, Saegert also sought to put the theories of Periere and Itard into practice. Like Seguin, he used physiological methods of treatment, concentrating on movement and in 1845 opened a private institution for the treatment of people with learning disabilities. Unlike Seguin and Guggenbuhl, Saegert was successful, in so far as his methods were adopted throughout his native Germany, with the result that between 1846 and 1881 thirty-two training schools for people with learning disabilities, based on his methods, were opened (Heaton-Ward 1977).

Similar developments took place in the Scandinavian countries, and Norway became the second country in Europe to introduce compulsory education for people with learning disabilities (Heaton-Ward 1977). Likewise, Italy saw the development of institutions for the moral and intellectual education of people with learning disabilities who previously had been regarded as incurable. Here, the main protagonist was Montessori, whose educational methods live on today in schools bearing her name.

Although many of the leading actors in the development of the care and treatment of people with learning disabilities were physicians, the work they undertook was essentially educational rather than medical.

In America, the first public concern for people with learning disabilities is placed at 1848, when State monies were used to fund an experimental school for 'idiots' within the Perkins Institution for the Blind in Boston which subsequently became the Massachusetts School for Idiotic and Feebleminded Youth (Scheerenberger 1983). This was the result of agitation and lobbying by Samuel Gridley Howe (1801-1876), who was inspired by Seguin's work and by a visit to Guggenbuhl's colony (Switzky, Dudzinski et al. 1988). The success of this school encouraged the proliferation of similar schools throughout the United States and by the turn of the twentieth-century, twenty-four such institutions had been set up in nineteen states (Adams 1971). The original objective of such schools was to educate and train those persons with learning disabilities considered to be potentially independent in order that they could return to society and undertake socially valued roles (Wolfensberger 1975). Adams (1971) suggests that there are two possible reasons for the establishment of such schools by states when most of the work we would now regard as the remit of social services was undertaken by philanthropists. Firstly, it is posited that universal education was seen to be an inherent feature of democracy. Support for this view is sought in the fact that schools for the deaf and blind were also established during the same period. The second argument Adams makes is that the period was one which had seen attempts to break with past regimes for newer regimes where people had greater freedom both in social and personal affairs. This, Adams suggests, can be attributed to the desire for freedom which was manifested in the American War of Independence and the French Revolution. These events resulted in the liberation of more humanistic values and informed many areas of thought ranging from Rousseau's educational theories to Pinel's theories on psychiatric care (Adams 1971:24-25). This view is also taken by Switzky, et al (1988). Rothman (1971), on the other hand, sees the development of such institutions as part of a larger attempt at controlling, regulating and disciplining the workforce.

In England, during the 1830s and 1840s, a considerable amount of social legislation was passed, one example being the 1833 Factory Act. Such legislation tended to display two common factors. Firstly, a recognition that the community had a responsibility to care for those who could not care for themselves. Secondly, an emphasis on the role of a central inspectorate to ensure that legislation was enforced uniformly and to provide advice about 'current best practice' (Jones 1960). Scull (1993) suggests that these two components of Victorian social reform were the result of the influence of two competing 'philosophical systems', Evangelicalism and Benthamism. That is to say the ranks of the reformers included people from both factions with the result that both the humanitarianism and paternalism of the Evangelicals and the emphasis on expertise and efficiency of the Benthamites was combined. One aspect of interest to the social reformers was the treatment of the 'insane'. Following the appointment in 1828 of the then Lord Ashley, (later to become the 7th Earl of Shaftesbury) to the Metropolitan Commission for Lunacy a national movement for reform began. Following a number of failed attempts to introduce new legislation on the subject of 'lunacy', a Lunacy Act was passed in 1845. Following this Act, there was considerable progress in the care and treatment of people with mental health problems. For example, previous physical methods of treatment, such as whipping, cold water plunges, blood letting, and purges were discredited along with the use of mechanical restraints. Instead, 'moral treatment' methods were widely adopted following the successful experiment at the Quaker run York Retreat (Scull 1989). Additionally, some doctors started to develop a greater interest in mental health[4].

Interest in the care and education of people with learning disabilities was predominantly inspired by the publication of articles on the achievements of Guggenbuhl and the work of Seguin at the Bicetre. As a result of these articles, the enthusiasm of the Reverend Andrew Reed, following his visit to Guggenbuhl's 'colony' in 1847[5], and the support of Dr. John Conolly, Park House, Highgate was opened in 1848 as a temporary home for twenty-seven children with learning disabilities. This home moved in 1850 to another temporary home and then again in 1855 to a new 500 bedded institution, the Royal Earlswood (Heaton-Ward 1977). A similar institution, Starcross Asylum, opened in Exeter in 1864, and in 1870 the foundations for another, the Northern Counties Asylum for Idiots and Imbeciles, were laid. Unlike the United States, institutions such as Park House were not originally established with State or local authority funding, but relied on charity. Amongst the first public ventures was the Darenth Training School, built by the Metropolitan authorities in the 1870s, prior to the enactment of the 1886 Idiots Act (Gilbert 1985). As in the rest of Europe and in America, the aim of such early English institutions for people with learning disabilities was to provide residential training in order that the individuals could be returned to the community where they could live ordinary lives (Heaton-Ward 1977; Braddock 1988). This early aim soon diminished following a realisation that some individuals were not improved by education. The corollary of this was that the aims of such institutions quickly became 'amelioration' rather than 'normalcy' (Kanner 1964).

The 1886 Idiots Act came about predominantly as a result of the lobbying of the *Charity Organisation Society*. The society, which was founded in 1868, had as its

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[4] For 'in depth' discussion of the 'lunacy' reforms see Jones (1972) and Scull (1989).

[5] A small school for 'idiots' taking four pupils had been established in Bath in 1846, but the establishment of Park House is generally recognised as the real beginning of the movement for the education of people with learning disabilities in England (Jones, 1960; Kanner, 1964).

main aim the co-ordination of all kinds of charitable effort. One of its council members was Sir Charles Trevelyan. In 1875 he advised the society's council that he believed that government should act in relation to the provision of education for 'improvable idiots'. In support of his view, he published a pamphlet on the subject and also obtained a letter from the Lunacy Commissioners expressing their agreement. In response to this, the council set up a sub-committee to debate the issue during the winter of 1876-7. The sub-committee, in their report, concluded that special provision for this class of persons was necessary due to their belief that they were not adequately cared for in existing institutions such as the workhouse or 'lunatic' asylum. The report was presented to the Local Government board by a deputation from the society headed by Shaftesbury. The report was accepted in principle, although the resulting legislation, the 1886 Idiots Act was disappointing (Jones 1960).

The Act, which received Royal Assent on the 25th June 1886, did not apply to Scotland or Ireland, and was essentially concerned with the admission of 'idiots' and 'imbeciles' to hospitals, institutions and licensed houses, the registration and inspection of such premises, and various requirements relating to record keeping. Additionally, it made provision for superannuation allowances to officers or servants of not less than fifteen years service. One important aspect of the Act was that it specifically distinguished between people with learning disabilities and those with mental health problems. However it would appear that this recognition of 'difference' had little impact on the placement of people with learning disabilities. This was particularly the case with individuals with learning disabilities who fell foul of the law (Scheerenberger 1983; Digby 1996). Unlike 'lunatics' who were acknowledged by the judiciary as being unaccountable for their actions from as early as 1800[6], people with learning disabilities who committed crimes continued to be sent to prison rather than to an 'idiot asylum'. In fact, although the early aim of recognising difference was to provide improved care for people with learning disabilities it frequently disadvantaged them. As Scheerenberger (1983) notes, the identification of a person as an 'idiot' often resulted in them losing civil rights they had previously enjoyed. For example, they lost the right to convey property, to be represented in their absence by a lawyer, to appear as a witness,

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[6] In the case of Hadfield (1800) 27 State Trials, 1281. The concept of insanity as a defence was developed from this case and resulted in the M'Naughten Rules of 1843 (10 C & F 200) which remains the basis of the law even today Norrie, A. (1993). Crime, reason and history: A critical introduction to criminal law. London, Weidenfeld & Nicolson.

and if they married this could later be annulled as a result of their 'idiocy'. Moreover, the Act was of little value in promoting the growth of educational establishments for people with learning disabilities in so far as few local authorities sought to provide such institutions (Jones 1960). Possibly as a result of this, four years after it was enacted, the legislature, by way of the 1890 Lunacy Act, ceased to differentiate between people with learning disabilities and mental health problems[7]. This Act was the result of public concern over illegal detention in private 'madhouses', often claimed to be undertaken in order that unscrupulous family members could gain access to the 'lunatics' estate. Because of this concern, the Act, despite the intentions of Shaftesbury and other reformers, was predominantly concerned with the introduction of numerous safeguards aimed at preventing the illegal detention of the 'sane', rather than with improving the well-being, care and treatment of 'lunatics' or people with learning disabilities (Jones 1960).

1.3.4. 1890 – 1954 The Period of Public Alarm and subsequent hiatus in policy:

Despite (or in spite of) the apparent failure of the 1886 Act, *the Charity Organisation Society* continued to gather evidence on the subject of the educability of the 'feeble-minded', as people with learning disabilities had come to be referred to. It did so, in association with the *British Association*, by way of a survey of London children in elementary schools and Poor Law Institutions. Following the success of experimental 'special' classes organised by, amongst others, the London County Council, the Elementary Education (Defective and Epileptic Children) Act was passed in 1899. This gave all local authorities the power to create special schools or classes for 'defective' children under the age of sixteen (Gilbert 1985). As with the 1886 Act, no duty was placed on local authorities to make such provision. Rather, the Act was merely permissive.

However, at the same time that *The Society* was promoting education for 'improvable idiots', it was also vocal in relation to the then current debate, about degeneracy generally and more specifically about the 'feeble-minded'. This debate was occurring simultaneously on both sides of the Atlantic and use was made of American thought in England as will be discussed later. The society itself

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[7] In the section on definitions, it provides "'Lunatic' means an idiot or person of unsound mind:"

grew and in 1896 became the *National Association for the Care of the Feeble-Minded*, which was to become highly influential in shaping future policy relating to the 'feeble-minded' (O'Connor and Tizard 1956; Jones 1960; Gilbert 1985) as will be discussed below.

As early as the 1860s, there was a growing debate about the 'problem' of 'degeneracy'. The concern about 'degeneracy' related to a perceived increase in the number of paupers, vagrants, alcoholics, criminals, delinquents, prostitutes and sexual deviants (Adams 1971; Hawkins 1997). It was believed that such persons were a threat to the fabric of society (Heaton-Ward 1977).

After 1890 the 'feeble-minded' became a central focus of this debate (Digby 1996). This was for a number of reasons, including; a perceived increase in the number of people with learning disabilities, the rise of Social Darwinism, the 're-discovery' of Mendel's Laws of inheritance, the rise of the eugenics movement and a growing belief that low intelligence was connected with other aspects of degeneracy such as crime, prostitution and alcoholism (Jones 1960; Kanner 1964; Adams 1971; Wolfensberger 1975; Fox 1978; Gelb 1987; Switzky, Dudzinski et al. 1988). These reasons are expanded upon below.

1.3.4.a. Reasons for public alarm

1.3.4.a.i. Industrialisation:

A number of reasons have been posited for this perceived increase in both the number of 'degenerates' and the number of people with learning disabilities. One of the more popular arguments is that whilst the economy had largely been built upon agrarian subsistence there was no need for people to undertake activities such as reading and writing. As a result of this only individuals with severe disabilities had been noticed. Those with milder disabilities had often worked alongside their families. Where individuals were unable to work, they were cared for by family members. However, as a result of the urbanisation and industrialisation of society resulting from such things as the Enclosure Acts and the industrial revolution, disabled individuals were unable to find appropriate work. Moreover, due to the economic need for the whole family to work people could not afford to remain at home to care for their disabled family members (Morris 1969; Adams 1971; Scheerenberger 1983; Gilbert 1985; Switzky, Dudzinski et al. 1988; Hawkins 1997). Additionally as a result of environmental changes and medical advances, more disabled infants survived childhood than had previously (Gilbert 1985).

1.3.4.a.ii. The Growth of Capitalism:

A second, slightly alternative argument is propounded by Scull (1989). Like the aforementioned writers, he posits the view that there was not a rise in the number of people with learning disabilities and mental illness or who were otherwise perceived as 'deviants'. However, he then suggests that a need to identify different types of deviant developed in the late eighteenth-century. He dismisses the vagueness of the 'urbanisation / industrialisation' argument and states that the recognition of people with learning disabilities and other 'deviants' was the direct result of capitalism. Firstly, he argues that from the late eighteenth-century capitalism undermined the old social order which resulted in a change from a, "*...master-servant to an employer-employee relationship...*" (1993:31) or from, "*...a paternalistic social order dominated by rank, order and degree to a society based on class*" (Scull 1989:217). He argues that whilst the result of this was the closing of alternatives to wage labour, employers took the view that all they owed their employees was wages. The corollary of this was that any family member unable to contribute towards the survival of the family became a major drain on family resources. He further argues that the establishment of the labour market provided the impetus for distinctions to be drawn between different types of 'deviant'. That is to say, in order for the labour market, and thus capitalism to flourish, it was necessary to distinguish the able-bodied from the non able-bodied as provision of relief to the able-bodied would undermine the labour market. He supports his argument by drawing his reader's attention to the fact that most of the early asylums were built in non-industrialised localities and had only local catchment areas (Scull 1993). A further argument he posits is that it was in the interests of the emerging caring professions, and in particular doctors that, "*...an expansionary view of madness...*" be adopted (1989:242). Additionally, he argues that the move from a society that was 'Providence-dominated' and based on religious and superstitious beliefs to one that was based on knowledge, science and rational explanations resulted in a belief that nature, including human nature, could be improved through intervention. That is to say that having seen that selective breeding of stock might result in improved animals and that raw material could be transformed through manufacture; people began to believe that such manipulation might be applied to human kind. In order to improve 'deviant' humans, however, one first had to identify and segregate them into appropriate categories (Scull 1993:104-110). Wolfensberger (1975) also posits the view that laissez-faire socio-economics were a cause of the increased visibility and growing negative perception of people with learning disabilities.

1.3.4.a.iii. Social Darwinism:

Social Darwinism was a combination of biology, politics, philosophy and the social sciences (Jones 1980). Social Darwinists claimed that Darwin's evolutionary theory, published in 1859, explained the superiority of European civilisation over 'primitive' (and 'coloured') societies in so far as they saw such people as being atavistic. They believed that people with learning disabilities were like members of an inferior race and that they were both a threat to the progress of mankind and an unnecessary burden on rate and tax-payers. Such beliefs were no doubt encouraged by the work of people such as Down who classified people with learning disabilities along racial lines (Scheerenberger 1983).[8] The application of Darwin's theory of the 'survival of the fittest' was seen to legitimise the ideology of laissez-faire individualism and thus capitalism, in that it was considered 'natural' that the 'fittest' firms would survive whilst the 'unfit' would fail. This view was then used as a counter-argument to social reformers' calls to improve the conditions of groups of people such as 'workers' or 'the poor' (Jones 1980; Bowler 1993; Dowbriggen 1997). This view that social interventions would cushion the 'unfit' from the impact of 'natural selection' was frequently taken by eugenicists such as Galton (Galton 1905b). Even Darwin himself expressed such a view at times (Hawkins 1997). Rather than wishing to protect, care for, or improve conditions for the 'feeble-minded' Social Darwinists believed that 'natural selection' should be

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[8] Despite organising his classification of people with learning disabilities according to ethnic similarities, hence 'mongol', Scheerenberger argues that this was not done as a result of Down perceiving any particular race negatively. Rather, he suggests that Down adopted this method in an attempt to alleviate parental guilt or the blame of others for the child's condition. That is to say he hoped that his classification would imply that "... the origin of idiocy existed before birth and was universal in character..." (Scheerenberger, 1983: p.57).

allowed to take its course with the result that the 'feeble-minded' would eventually become extinct (Morris 1969).

1.3.4.a.iv. Mendelism:

Gregor Mendel was an Austrian monk who had carried out experiments on peas. He found that rather than offspring taking traits equally from both parents, some traits were dominant and others recessive. He also discovered that it was possible to 'breed out' certain traits. His work with peas was originally published in 1866, however, until its 're-discovery' in 1900 by De Vries and his associates it was largely unnoticed (Scheerenberger 1983; Rafter 1997; Timson 1998). Prior to the 're-discovery' of Mendel's work whilst heredity was thought to be a major cause of learning disability and mental illness, 'heredity' was given a broad meaning at that time. It was commonly used to refer not only to genetic transmission, but also to pre-natal, natal and postnatal injuries and the transmission of learned characteristics (Scheerenberger 1983). In view of this belief, generally referred to as 'Lamarckism', after the French naturalist Jean Baptiste de Lamarck who devised this theory, social reforms, such as improved education, made sense as the gains made by a person in their lifetime would be passed on to their offspring. Mendelian Heredity, however, dismissed the role of the environment, and focused on the 'germ plasm' (Jones 1980). Despite the recognition that accidental and parental factors might also be factors in learning disability (Scheerenberger 1983) emphasis was placed on Mendelian Heredity by geneticists of the period, Social Darwinists and eugenicists (Jones 1980) . As a result of this, the value of social reform was questioned. Not only this, but it was also thought that people with a learning disability would bear offspring with a learning disability. Given the belief that the 'feeble-minded' were more fecund than the middle and professional classes, which stemmed from studies undertaken by eugenicists and will be discussed later, there was concern that the race would be weakened (Fox 1978). The 'mad', who were also seen as fecund were perceived to present a similar threat to the race (Scull 1993).

1.3.4.a.v. The Eugenics Movement:

Although Mendelian Heredity was different to, and eventually superseded Galton's own idea of heredity (Timson 1998), 'Biometrics'[9], eugenicists frequently used Mendel's Laws of Inheritance for their own purposes (Bowler 1993). Francis Galton, a half-cousin of Charles Darwin had, in 1865, expressed his concern that the 'unfit' posed a threat to the 'fit' as a result of their high birth-rate (Kanner 1964; Jones 1980). The 'feeble-minded' were not the only group seen as 'unfit', people with mental health problems and the unemployed poor were also seen in this light (Searle 1976), However, it was the 'feeble-minded' in general and 'feeble-minded' women in particular who attracted the most attention (Digby 1996; Gladstone 1996). In 1869, in his *Hereditary Genius*, he claimed to show that 'greatness' followed in family lines so frequently that one could conclude that a persons' abilities were inherited from their parents (Scheerenberger 1983). In 1883, he conceived the term 'eugenics' to refer to, *"...the science which deals with all influences that improve the inborn qualities of a race"* (Blacker 1950; Kanner 1964; Dennis 1975). In 1907 Galton adapted his definition to, *"...the study of the agencies under social control that may improve or impair the racial qualities of future generations, either physically or mentally"* (Dowbriggen 1997). The aim of eugenics was thus to, *"...represent each class or sect by its best specimens..."* (Galton 1904: pp.36-7).

Some writers have sought to conflate Social Darwinism and eugenics (Jones 1980). In doing so, they point to similarities between the two movements. Similarities include the fact that both Social Darwinists and early eugenicists not only attacked the 'degenerate' but also the aristocracy arguing that aristocratic privilege prevented evolutionary progress (Searle 1976; Jones 1980). Additionally, both Darwin and Galton, though in different ways, had been influenced by the work of Malthus. Malthus, a clergyman, had looked for causes of the civil unrest, which was widespread throughout Europe in the late eighteenth-century. In his *Essay on the Principle of Population*, first published in 1798, he concluded that the unrest was due to the impoverished condition of the poorer classes. However, he placed the blame for their condition on their large families, positing the view

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[9] Galton believed that 50% of a child's make up would be derived from each parent, who in turn would have received 50% from each of its parents, thus a child would receive 25% of its genetic makeup from its grandparent, 12.5% from their great grandparents, etc. In Mendel's Law, however, there is no statistical division of heredity, rather, he emphasises the role of dominant and recessive genes Jones, G. (1998). Theoretical foundations of eugenics. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute: 1-19.

that having large families caused an abundance of labour which had to compete for a limited amount of work. The corollary of this was that the wages were driven down (Ledbetter 1976). He further argued that the growth in population was putting pressure on the existence of society and expressed the view that population pressures would prevent the further development of society (Jones 1980). In order to alleviate the situation, he advocated birth control in the form of late marriage or sexual abstinence (Ledbetter 1976). Whilst Galton ascribed to Malthus' view, and Neo-Malthusians and the *Eugenics Society* actually combined forces at times, Darwin did not. Rather, he argued that the growth of the population would further social evolution (Jones 1980). Additionally, despite the fact that Galton had been influenced by Darwin's *The Origin of the Species* and generally accepted the thesis that the laws which governed the evolution of plants and animals applied to humankind, he did not believe that 'natural selection' was sufficient. Rather, he believed that humans should not allow nature to 'take its course' but that they should consciously intervene to alter the course of their development (Blacker 1950; Bowler 1993; Timson 1998). Moreover, Galton found it hard to reconcile the theory of 'natural selection' with the fact that the 'unfit' appeared to be more fertile than the 'fit' (Jones 1980). It is clear, therefore, that whilst eugenics was closely associated with Social Darwinism the two movements were different and should not be conflated (Hawkins 1997).

Galton had little success in promoting his hereditarian policies in the 1880s due to the then current belief that self-improvement was not only possible but should be encouraged (Jones 1980; Bowler 1993; Hawkins 1997). This belief was even expressed by Galton in a lecture he delivered in 1901 (Galton 1901). His ideas did not, in fact, become influential until the early twentieth-century. A number of reasons have been posited as to why such ideas became influential.

One reason suggested was the discovery that the birth-rate of the middle and upper classes was declining faster than that of the 'worthless' such as the poor unemployed (Blacker 1952; Hawkins 1997; Searle 1998).

A further reason posited for the sudden popularity of eugenics was the concern that arose as a result of the South African Boer War (1899-1902) when it was found that many potential recruits had both low levels of health and intelligence

(Searle 1976; Jones 1980; Hawkins 1997). This finding resulted in concern being expressed as to the 'vitality of the nation'.

A third reason relates to the fact that people with learning and other disabilities who were seen as 'unfit' were seen to place a huge burden on the 'fit' members of society. Eugenicists believed that high levels of taxation were one of the factors that prevented 'fit' persons from having large families. Eugenics was thus promoted as a means of reducing taxation (Searle 1976). Although the eugenics movement was not isolated in its views on degeneracy and the 'feeble-minded' it is argued by Hawkins (1997) that the eugenics movement provided a convenient framework for thinking about such issues. This is due to the fact that it brought together various phenomena such as crime, 'feeble-mindedness', poverty, moral depravity, issues relating to the family, abortion, birth control and the powers and responsibilities of public and private or charitable agencies. Not only did it bring together such phenomena, but it allowed such concerns to be addressed, both within a cosmopolitan perspective, which expressed a concern for the future of the human species and, within the context of national consciousness in which the survival of the race was viewed as being of utmost importance (Searle 1976). The movement and more particularly the *Eugenics Society* were not generally influential in shaping public policy (Searle 1998), however, they did play an important role in the history of genetics. This was due to the fact that a number of prominent human geneticists were members of the *Eugenics Society* (Kevles 1995), and as a result of them informing the public of the importance of the role of genetics in shaping humankind (Timson 1998). More importantly, in relation to this study, the movement played a considerable role in maintaining the 'public alarm' about the 'feeble-minded' and in the introduction of the 1913 Mental Deficiency Act. This role will be discussed in more detail below.

Galton argued that it was necessary to promote the birth-rate of the 'fit', which he termed 'positive eugenics' whilst at the same time reducing the offspring of the 'unfit' which he termed 'negative eugenics' (Switzky, Dudzinski et al. 1988). However, unlike some members of the *Eugenics Society*[10], he urged that any crusade in favour of race improvement be thoroughly justified by way of unbiased scientific enquiry (Galton 1901). As a result of this belief combined with his strong interest in statistics he sought to apply statistical concepts to biological

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[10] Called the Eugenics Education Society until 1926

development (Jones 1960), which he referred to as 'biometrics'.[11] He subsequently left a substantial bequest for the funding of a Biometrics Laboratory and a chair in eugenics at London University of which Karl Pearson was to be its first incumbent (Searle 1976; Jones 1980).

In America, a number of family studies were undertaken, predominantly by eugenicists. These claimed to apply Mendel's laws of inheritance and were in the form of genealogies. These studies were interpreted (or misinterpreted) to suggest that behaviour that would probably now be referred to as 'sociopathy' or 'psychopathy' was inherited (Fox 1978). One of the first of these studies was carried out by Dugdale (1877), a penologist, into the Juke family. Interestingly, Dugdale himself did not interpret his findings as being the result of hereditary factors. Rather, he ascribed his findings to environmental factors. Hereditarians, however, concluded that his study of the Jukes showed inheritance to be more potent than the environment in determining learning disabilities and degeneracy (Scheerenberger 1983; Dowbriggen 1997). After Dugdale's study, which itself was followed up in 1915 by Estabrook (1916), there was a flurry of similar studies in both England and the United States (Dowbriggen 1997). One such (in)famous study is that of the Kallikaks by Goddard (1912). The methods used to undertake such 'research' were considered doubtful, even shortly after they were completed. This was partly due to the fact that a large number of the people included in the studies had died prior to the study and it was thus not possible to test their intelligence. A further criticism of the studies was that the application of statistics to biological development gave a false picture, as it did not take account of environmental factors. Despite such faults the studies were used, with effect, to support the belief that learning disability was hereditary and to promote the eugenic belief that such persons should be prevented from having offspring both in the United States and in England and Wales (Jones 1960; Morris 1969).

Such studies purported to demonstrate not only that learning disability was inherited, but that it was a factor in all other forms of degeneracy (Morris 1969; Switzky, Dudzinski et al. 1988). The studies were also cited as evidence that the 'feeble-minded' were more fecund than the middle and professional classes (Morris 1969; Switzky, Dudzinski et al. 1988; Dowbriggen 1997).

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[11] See footnote 10 above.

A further reason for both the apparent increase in the numbers of 'feeble-minded' and the association of low intelligence with other forms of degeneracy was the development and widespread introduction of intelligence testing (Adams 1971; Fox 1978). Intelligence testing was to become the primary means of identifying people with a learning disability and was thus an important precursor to their segregation (Digby 1996). A number of people were interested in the idea of intelligence testing during the latter decades of the nineteenth-century (Scheerenberger 1983). For example, Galton had undertaken some work on intelligence testing which had been adopted and adapted in America by J. McKeen Catell who published his first major study in 1896 (Jones 1960; Scheerenberger 1983). However, it was not until Binet and Simon had published their intelligence tests in 1905 that intelligence testing became fashionable and widespread. Binet, who had criticised the earlier 'sensationalists' such as Itard and Seguin (O'Connor and Tizard 1956), had been appointed in 1904 by the French Minister of Public Instruction to undertake research on children with learning disabilities. His brief was to devise a means of ascertaining which children were unlikely to be able to adapt to the curriculum. This was because such children were seen to, "*...reduce the efficiency of the teachers*" (Kanner 1964:120). Their tests, which were seen to have introduced a scientific method into the field of intelligence testing (Jones 1960), were adapted in the United States by Goddard (O'Connor and Tizard 1956; Kevles 1998) and used widely to classify 'feeble-minded' children (Gelb 1987).

In England, intelligence tests were widely carried out from 1907 onwards. It was reported that there was a negative correlation between innate intelligence and size of family, thus the more intelligent, professional classes had smaller families than the less intelligent poorer classes. Given this finding and the belief in heredity of intelligence, it was almost inevitable that people came to the conclusion that unless something was done about this 'differential fertility' the average level of intelligence of the race would decline (Burt 1952). Additionally, intelligence testing was carried out in a number of prisons. The results of these tests suggested that a high proportion of crime was carried out by the 'feeble-minded' (Morris 1969; Jackson 1996)[12]. As a result of the belief that the 'feeble-minded' were more likely

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[12] A study carried out in 1913, by Charles Goring and Karl Pearson Goring, C. and K. Pearson (1913). The English convict: A Statistical Study. London, HMSO.

did not, however support this view, although they did find disabled criminals, a number of whom were, according to Morris (1969) and Searle (1976) 'feeble-minded'.

to be criminals, prison surgeons were amongst the leading protagonists of the movement for the segregation of the 'feeble-minded' (Digby 1996).

Despite widespread intelligence testing, numerous family studies and genetics studies, the cause of learning disability remained unclear. However, as a result of the above factors, people with learning disabilities came to be seen as a threat to society and were seen as being responsible for all forms of social degeneracy (Kanner 1964; Heaton-Ward 1977; Switzky, Dudzinski et al. 1988). Such a view was not only confined to eugenicists, but was widely held. For example, Cammack in his thesis on moral problems of 'mental defect', although against sterilisation on religious and moral principles, states, *"...the fact remains that mental defect is one of the material causes of material sin and crime..."* (1938:41). Such views were not only widely held in the UK but elsewhere in the world. For example, Dowbriggen (1997) notes that in Canada groups as diverse as suffrage associations, Christian temperance associations and Christian women's associations combined with eugenicists and imperialists in the fight against groups thought to be causing a decline in the race.

Given such beliefs, it is not surprising that suggestions aimed at reducing degeneracy and preventing learning disabilities emphasised the prevention of child-bearing by the 'feeble-minded'. Proposed solutions ranged from the temporary segregation of 'feeble-minded' females of child-bearing age to sterilisation.

Such beliefs were strongly held both in the United States and in England and Wales. In the United States, one of the main protagonists in the change of attitudes from 'hope through education' to 'control and prevention' was *the American Association on Mental Deficiency* (Scheerenberger 1983). Another group that had a large amount of influence was the *American Cattle Breeders' Association Eugenics Committee.* They suggested ten possible responses to the perceived problem of the degenerate including; euthanasia, restrictive marriage laws, eugenic education, scientific breeding, birth control or 'neo-Malthusianism', institutionalisation and sterilisation (Kanner 1964). Whilst some of these possible responses, such as euthanasia, were shunned, others, such as segregation and sterilisation were to come to fruition. Thirty-nine American states enacted legislation prohibiting the marriage of people with learning disabilities

(Scheerenberger 1983). However, despite the fact that so many states enacted such legislation, it was generally acknowledged that the laws would be ineffective, as prohibiting marriage does not necessarily prevent procreation. Others saw sterilisation as an alternative to marriage prohibition and it was first advocated in the 1890s (Wolfensberger 1975). The first recorded eugenic 'asexualisation' operation was performed on forty-four 'feeble-minded' boys at the 'Kansas State Home for the Feebleminded' in 1894. They were castrated by the superintendent of the home, Hoyt Pilcher. He was dismissed as a result of public uproar at the idea of 'asexualisation' by means of castration (Dowbriggen 1997). However, no such public clamour was reported three years later, in 1897, when the first vasectomy was reported (Blacker 1961; Dowbriggen 1997). Americans who argued that sterilisation or 'asexualisation' was preferable to segregation based their argument on a number of grounds. Firstly, it was argued that sterilisation would interfere less with the liberty of individuals, in that they would then be able to live in society and even marry. Secondly, it was promoted as being more cost-effective than long term incarceration (Wolfensberger 1975; Scheerenberger 1983). Additionally it was believed by some that sterilisation would control 'undesirable' sexual behaviours such as masturbation (Scheerenberger 1983). However, Scheerenberger (1983) states that most of the general public, the medical profession (c.f. Dowbriggen 1997) and politicians were unenthusiastic about sterilisation. His view is supported by the fact that seven of the first sixteen sterilisation laws had been struck down by federal or state courts as being unconstitutional prior to 1927 (Dowbriggen 1997). Wolfensberger (1975) also subscribes to this view stating that sterilisation was seen as unhelpful and likely to result in the encouragement of vice and the spread of venereal disease. Despite the alleged lack of enthusiasm for compulsory sterilisation, by 1912 eight states had passed legislation permitting sterilisation of certain categories of person, though only six of these specifically included 'idiots', 'imbeciles' and the 'feeble-minded' (Scheerenberger 1983). This number had risen to thirty by 1940 (Dowbriggen 1997). In some of these states the sterilisation could be carried out compulsorily. In others, people with learning disabilities were required to consent. However, such consent was hardly voluntary given that such individuals had the limited choice of being sterilised or permanently incarcerated (Scheerenberger 1983). Such laws remained in force until as recently as the 1970s (Hawkins 1997). Blacker (1962a) reports that in the period 1907 – 1960 some 62,162 sterilisation operations were undertaken in American State Institutions. Of that total, slightly over fifty percent were people with learning disabilities.[13] In addition to sterilisation, segregation and prohibition on marriage, many states passed further legislation that denied people with learning disabilities the civil rights enjoyed by others. Such legislation included removing the right to vote, the right to enter into contracts and the right to join the National Guard. Additionally some states prohibited the sale of alcohol or the sale of firearms to people with learning disabilities (Scheerenberger 1983). It was not until the 1920s that Americans began to see people with learning disabilities in a more positive light and started to develop small-scale community based and other alternatives to the large institutions. However, this positive attitude was, for various reasons, not to last (Wolfensberger 1975; Scheerenberger 1983). This can be seen from the 1927 case of Buck v Bell,[14] a Supreme Court decision, which held that eugenic sterilisation was constitutional and led to an increased use of sterilisation within state institutions for the learning disabled and mentally ill (Kevles 1998).

Similar eugenic measures to those taken in America were to be taken throughout Europe and Scandinavia (Drouard 1998).

In England, *The National Association for the Care of the Feeble Minded* appeared to change their aims in line with public concerns. They no longer called for the government to provide education for people with learning disabilities but instead began to promote 'life-long segregation' (Gilbert 1985). Jones (1960) and Jackson, (1996) suggest that much of the *Association's* influence on policy making was the result of two women, Mary Dendy and Hume Pinsent. Even before the founding of the *Eugenics Society* in 1908, these women had written articles and pamphlets, which Mrs Pinsent had distributed amongst members of parliament and local authorities, advocating their proposed state scheme for the permanent care of the feeble-minded. Such was their influence that they were cited as being 'weighty authorities' in the second reading of the 1913 Mental Deficiency Bill (Hansard, 28/5/1913, col. 232; 3/6/1913, col. 832). Hume Pinsent was later to become one of the members of the Wood Committee, discussed below.

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[13] Blacker Blacker, C. P. (1962a). "Voluntary sterilization: Transitions throughout the world." Eugenics Review 54(3): 143-162.

reports that 11, 217 learning disabled males and 21, 070 learning disabled females were sterilised. Additionally, 1,181 epileptic males and 1,102 epileptic females were sterilised.

Mary Dendy and Hume Pinsent both became members of the *Eugenics Society,* which, as stated earlier, played a considerable role in the introduction of the 1913 Mental Deficiency Act. The *Eugenics Society,* which was founded in the winter of 1907 – 1908, started life as a break-away group of the *Moral Education League* (Searle 1976). The main aim of the *Eugenics Society* was to present eugenics as a, *"...science of man that... (would make) redundant all previous speculations in philosophy, history and sociology"* (Searle 1976: p.1). Interestingly it based its programmes neither on Biometrics or Mendelian Law but on a, *"...vague sentiment about the importance of heredity"* (Jones 1998: p.16).

The *Eugenics Society* grew rapidly and a number of eminent physicians expressed views favourable to eugenics or were members of the *Eugenics Society*. They included Sir James Barr, president of the British Medical Association in 1913, James Crichton-Browne, the Lord-Chancellor's Visitor in Lunacy and the author of a number of mental health texts and Drs. Tredgold, and Rentoul, both of whom were amongst the experts upon whom the 1904 Radnor Commission relied. Tredgold was also the author of one of the leading texts on mental deficiency. Thomas Clouston and Henry Maudsley, two of the most respected English psychiatrists of the era also wrote a number of pro-eugenic articles expressing the view that the hereditary transmission of antisocial traits was likely to negatively affect the evolution of society (Searle 1976; Dowbriggen 1997).

Although Galton urged the prohibition of marriage of the 'unfit' (Galton 1905) his main emphasis was on positive eugenics (Searle 1976). He favoured the use of a method of certification to encourage 'eugenically suitable' marriages (Galton 1905a). Although Galton was not involved in the formation of the Eugenics Society or its early development (Peel 1998)[15] its original emphasis, which for the most part, continued throughout Leonard Darwin's presidency (1911-1928), was also on positive eugenics (Solway 1998). For example, Searle (1976) reports that, as late as 1914, the official line on the sterilisation of 'defectives' was not only that its justification was doubtful but that the issue should not be pressed in England. However, despite wishing to emphasise positive eugenics, eugenicists found it

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[14] Buck v Bell, 274 US 201-207

[15] Searle (1976) reports that the reason for Galton's early reluctance to associate with the society was due to it being run by a young American doctor in whom he had little confidence.

particularly difficult to define who or what was worthy and thus who should be encouraged to breed. On the other hand, it was relatively easy for them to define the 'unworthy' or 'unfit'. The corollary of this was that whilst they wished to promote the breeding of the 'fit' or 'positive eugenics', they were more frequently seen to be promoting 'negative eugenics' (Solway 1998).

1.3.4.b. The Royal Commission into the Care and Control of the 'Feeble-minded':

Although the issue of 'feeble-mindedness' was in the public domain prior to 1908, the Report of the Royal Commission into the Care and Control of the Feeble-minded heightened public awareness of the so-called 'problem' (Searle 1976). The Commission was chaired by Lord Radnor and was appointed as a result of concerns expressed by the Poor Law and Prison authorities that they were having to maintain 'feeble-minded' individuals as a result of there being no suitable alternative provision for them (Searle 1976)[16]. Royal Commissions are generally expected to gather evidence and then present an unbiased report based on that evidence. However, in this case it is arguable that the report was biased in favour of eugenic principles due to the fact that many of its members were themselves members of the Eugenics Society (Hansard, 10/6/1912, col. 644). Part I of the Commission's report provides the reader with numerous descriptions of 'the problem', which appears to be a combination of alcohol dependence, promiscuity, pregnancy out of wedlock with no means of self support, lack of social skills and aggression. The problem of the 'feeble-minded' was thus framed in terms of social rather than educational deficit. Part IV of the report is concerned with the link between 'mental defect' and crime. In the report, the Commissioners cite the evidence of Dr. Scott of Brixton Prison. Although he expresses the view that people with learning disabilities who commit crimes should not be held responsible for their actions, his views are clearly influenced by eugenics, hence, after providing a list of negative attributes, he states,
'...(i)t is also important to consider from the point of view of the improvement of the race, if any means can be taken to prevent these 'undesirables' from producing their like' (Royal Commission 1908: p.117).

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[16] This is evident from the Second Reading of the Mental Deficiency Bill. See Hansard Commons Debates, Series 5, 10/6/1912, col. 628.

Although the Commission acknowledged a diversity of opinion in relation to whether learning disability was heredity, they neatly side-stepped the issue. They did so by listing a number of issues concerned with parenting by people with learning disabilities and concluding that,

"*There can be no doubt that feeble-minded parents do not and cannot bring up their children to be satisfactory members of the community...*" (Royal Commission 1908: p.181).

The Commission was widely influenced by the American use of institutions to prevent the breeding of the 'feeble-minded' (Digby 1996). Whilst they framed one of their recommendations in terms of the protection of people with learning disabilities against "*sexual crime and immorality*" (Royal Commission 1908: recommendation XCV) the paragraph on which they based this recommendation was more concerned about the sexual behaviour of the 'feeble minded' rather than protection. The paragraph states,

"*...the aberrations of mental defect and disorder often take the form of sexual offences and impropriety...*" (Royal Commission 1908: p.154).

In fact, the Commissioners framed the majority of their conclusions in terms of protection of the 'mentally defective' and of the community. Although they considered the prohibition of marriage, as was called for by some of the witnesses, they expressed the view that it was neither efficacious nor enforceable. Their main recommendation was that certain classes of the 'mentally defective' should be segregated from the rest of the community in the interests both of their protection and the protection of the community at large.

1.3.4.c. The 1913 Mental Deficiency Act:

Subsequent to the report of the Commission being published in 1908, a number of questions were asked in the House of Commons prior to 1911 as to when legislation would be forthcoming. Additionally a considerable campaign for legislation was undertaken by the *National Association for the After Care of the Feeble-Minded* and the *Eugenics Society* (Jones 1960; Searle 1976). However, the government was slow in introducing such a Bill. After the 1910 general election the *Eugenics Society* started to act as a pressure group and over the following three years sought to cultivate MPs to their point of view concerning the segregation of the 'feeble-minded'. In October 1910 the above two organisations joined forces and sent a deputation to visit the Prime Minister. The following March they collaborated on the drafting of a short Bill, the Feeble-Minded Persons (Control) Bill. In November 1911 they set up a Parliamentary Committee to follow the progress of Bills going through parliament, the content of which, was of interest to eugenicists (Jones 1960; Searle 1976). On 17 May 1912 the Feeble-Minded Persons (Control) Bill was introduced as a private member's Bill by Gershom Stewart. During the second reading of the Bill, McKenna, then Home Secretary, introduced the government's own Bill, the Mental Deficiency Bill. This Bill was clearly influenced by eugenicists and contained clauses providing, *inter alia*, for the detention of those,

"...in whose case it is desirable in the interests of the community that they should be deprived of the opportunity of procreating children"

and those not capable,

"...of managing themselves and their affairs with ordinary prudence."

It also sought to forbid the marriage of the 'mentally defective' to 'non-defectives'. The machinery of the Bill was criticised as was its poor drafting. Additionally three members of the House of Commons attacked it on the grounds of it being based on eugenics and as being too drastic a measure. Despite these criticisms the Bill passed its second reading on July 19, 1912 by 230 votes to 38. However, the Bill never proceeded further and a newly drafted form was introduced to the Lower House on March 25, 1913. In introducing the new Bill, McKenna referred to the changes that had been made following the criticisms of the previous Bill. In particular, the clause relating to the compulsory detention of persons whom it was thought in the interests of society that they should be derived of the opportunity of procreation, along with the clause prohibiting marriage with a 'defective' had been removed. McKenna specifically sought to assure members that the Bill's main concern was with the protection of individuals and not eugenics, stating that,

" We have omitted any reference to what might be regarded as the Eugenic idea" (Hansard, 28/5/1913, col. 221).

Despite the amendments to the Bill, it was once again criticised on the grounds of it being an attack on individual liberty, because it was based on a belief in heredity, that it was aimed at the 'lower orders', because the definition was not clear and because it was felt that the government had underestimated the cost implications of the Bill. However, other Members of the House were more positive about the Bill and cited the fact that they had received large petitions in its favour from Trade Unions, Co-operative Guilds, Trades Councils and a variety of churchmen. The Bill passed its second reading by a vote of 273 to 96 and went to committee where it was amended, and a number of new clauses proposed. The new clauses relating to such things as abolition of the death sentence for 'mental defectives', alternative definitions of 'mental deficiency', and the introduction of a new class, the 'sexually feeble-minded', were debated in considerable depth over a two day period. Considerable emphasis was placed on the need for a clearer definition of 'mental deficiency' than was contained in the Bill. However, despite the attempts of Members such as Wedgewood and Goldsmith to thwart the Bill, the majority of the house voted that the Bill be read for a third time. The Bill went to the House of Lords who sought certain amendments. The Lords' Amendments were minor and were agreed to with the result that the Bill was enacted on August 15th 1913. Although much of the eugenic content had been removed, the Act still satisfied the eugenicists desire to prevent the procreation of the feeble-minded through its compulsory powers of detention and segregation (Searle 1976).

The 1913 Act comprised of some 72 sections. Part one of the Act relates to the powers and manner of dealing with 'defectives'. It defined defectives with reference to social inadequacy rather than intellectual capability. It also provided for the circumstances under which a defective might be dealt with under the Act by placing them in an institution or under guardianship. In the first instance it provided that this could occur at the request of the parents of an 'idiot' or 'imbecile' at any age or at the request of the parents of 'feeble-minded' or 'moral imbeciles' if the individual was under twenty-one years of age. Additionally it provided that 'defectives' could be dealt with under the Act if they were, *inter alia*, lacking support, had been cruelly treated, had been found guilty of a criminal offence, were detained in a variety of other institutions, were alcoholics, or, if having attended a special school or class, it was thought by their education authority that they would benefit from being treated under the Act. Additionally, the Act specifically provided that defective females who gave birth to, or were pregnant with an illegitimate child whilst in receipt of poor relief could be dealt with by the Act. Part II of the Act related to the powers and duties of central and local authorities, Part III of the Act related to the certification and provision of institutions and Part IV of the Act was general and contained miscellaneous offences and legal proceedings under the Act.

Section 56 of the Act was specifically concerned with sexual acts. It created five offences. Firstly, it made it an offence for any person to,

"...unlawfully and carnally know or attempt to know any woman or girl under care or treatment in an institution ...or whilst placed out on licence therefrom or under guardianship under..."

the Act. Secondly it made it an offence for any person to,

"...procure or attempt to procure any woman or girl who is a defective to have unlawful carnal connection... with any person or persons."

Thirdly, it made it an offence for any person to,

"...cause or encourage the prostitution... of any woman or girl who is a defective."

Fourthly it made it an offence for the owner, occupier or anyone acting in the management of any premises to,

"...induce, or knowingly suffer any woman or girl who is a defective... to be on the premises for the purposes of being unlawfully and carnally known by any man..."

Finally, it made it an offence for any person to take a female 'defective' out of the control of her parent or lawful carer for the purpose of her being, *"...unlawfully and carnally known by any man"*.

All offences carried a sentence punishable by up to two years imprisonment with or without hard labour and consent by the defective woman was no defence. The only defence was for the accused to show that he neither knew nor had reason to suspect that the female was 'defective'. The section also provided for the possible situation where a person may be tried for rape and the jury was not satisfied that he had committed rape but were satisfied that he had committed the first offence described above. In such a case, he would be found not guilty of rape, but would be convicted of the first offence outlined above and thus be subject to a maximum of two years imprisonment. It can thus be seen that the 1913 Act introduced a number of means of controlling the expression of sexuality of females with learning disabilities and those who might have entered into relationships with them. Despite the passing of almost ninety years, that law remained virtually intact at the time of this study and, as will be discussed in a later section of this dissertation, may be perceived as one of the factors contributing to the prevention of the expression of sexuality by people with learning disabilities.

Until recently, little had been written about the history of people with learning disabilities between the passage of the 1913 Act and the run up to the introduction of the 1959 Act or about the workings of the 1913 Act. In an attempt to overcome this dearth of literature, the little available writing has been supplemented in the next part of this section by reference to such things as Hansard and parliamentary papers.

Provisional orders were made under the Act on March 26, 1914 which were to provide special reasons why a defective might be dealt with under the Act. One of the 'special reasons' widened the section relating to defective women, who gave birth to or were pregnant with an illegitimate child whilst receiving Poor Law payments. It further provided that defective women who were, "*...prostitutes, who lodged or resided with prostitutes or who lived in circumstances that were calculated to cause, encourage or favour her seduction or prostitution*" could also be dealt with under the Act (Parliamentary Papers 1914, No. 178). However, these orders appear not to have come into effect. O'Connor and Tizard (1956) state that a statutory instrument prevented the attachment of a 'defective' on licence to a person of the opposite sex. However, despite considerable searching no such statutory instrument appears to have come into force. Looking at Hansard, it would appear that the period 1914 to 1919 was quiet in relation to the discussion of people with learning disabilities, presumably as a result of the War (Jones 1960). In February 1919, it was noted that a number of people with learning disabilities had entered employment during the war as a result of the shortage of labour. It was further noted that those individuals would be amongst the first to lose their jobs once the troops returned. However, the concern was not for the people with learning disabilities losing their jobs or being returned to institutions but was in relation to the fact that now such individuals had become independent they may have contracted venereal disease which resulted them being, "*...quite a trap for the returning soldier.*" (Hansard, 26/2/1919, col. 1872).

There appears to have been little concern expressed about the way in which the Act was used. Hansard records only one such concern. This was expressed in June 1923 and related to the number of complaints being made about the exercise of the wide powers of the Act (Hansard, 27/6/1923, col. 2333). However, there was no adequate response to the question and no similar question was raised at a later date within the period in question. The 1913 Act was amended in

1925[17] in order to allow people to be transferred from institutions for the purpose of being placed under guardianship. A further amendment was made in 1927[18] which widened the definition of mental deficiency by altering the requirement that it was 'present from birth or an early age' to it being present before the age of eighteen. Other than this, no further discussion of people with learning disabilities took place in parliament until February 1926 when the issue of sterilisation was raised (Hansard, 4/2/1926, col. 301).

The lack of parliamentary discussion concerning people with a learning disability may be attributable to the fact that the Eugenics Society had pretty much dispersed during the First World War. As a result of this there was little call for eugenic legislation. However, by the mid 1920s, Leonard Darwin and other eugenicists had started to think along the lines that eugenic sterilisation would be cheaper than life long segregation. Shortly after Blacker took over as general secretary in 1931, the *Eugenics Society* undertook a campaign for voluntary sterilisation and the prohibition of marriage to persons thought to be 'unfit' (Searle 1976). At the same time, it became increasingly involved in the birth control movement, a relationship which it had first established in 1923 (Jones 1980; Hall 1998; Solway 1998).

1.3.4.d. The Wood Committee into the education of 'mentally deficient' children and the care, training and control of adult 'mental defectives':

In 1929, the report of the Joint Committee of the Board of Education and the Board of Control under the chairmanship of Wood was published. The Wood Committee had undertaken a study into the education of 'mentally deficient' children and the care, training and control of adult 'mental defectives'. They had also commissioned Dr. E. O. Lewis to undertake an investigation into the incidence of 'mental deficiency' within the population. The study by Dr. Lewis had assessed the incidence of 'mental defectives' in England and Wales as being approximately 8.56 per thousand of the population. This was almost twice the incidence given by the Royal Commission in 1908. The committee made a number of recommendations including that all educable 'mentally defective' children and 'dull' and 'backward' children should be treated as a single

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[17] Mental Deficiency (Amendment) Act 1925

[18] Mental Deficiency Act 1927

educational group, whilst 'idiot' and 'imbecile' children should be treated as a separate educational group. Educational provision was recommended for both groups. In relation to adult 'mental defectives', it was recommended that there should be a comprehensive scheme of care, training and control and that this should be the responsibility of a single authority. They also recommended the increased use of community care and licensing.

1.3.4.e. The call for sterilisation and the Brock Committee:

Although there had been calls for the introduction of sterilisation from as early as 1903 (Rentoul 1906), the *Eugenics Society* saw the presentation of the Wood report as being an opportune time to press for the sterilisation of 'defectives' as an adjunct to segregation (Blacker 1950; Kevles 1995). They drafted a Bill which, *inter alia*, prohibited the marriage of 'defectives' and mentally ill unless they had been sterilised or were infertile. They also published a pamphlet, *Eugenic Sterilisation*, setting out their beliefs as to sterilisation. A second edition of the pamphlet, which contained the text of a more comprehensive draft Bill was published in 1931 (Blacker 1952). Later that year they published a further pamphlet, *Better Unborn*, which described forty cases of 'irresponsible parenting' by people with 'borderline mentality' and contained a further draft Bill which provided that 'mental defectives' should be able to be sterilised on their application or the application of their spouses, parents or guardians. In July of that year, Major Church, Labour member for Central Wandsworth introduced the Bill under the ten minute rule, but it was heavily criticised by Dr. Morgan, another Labour member, who argued that it was anti-working class and that sterilisation was unhelpful. As a result of his argument the Bill was not accepted, the vote being 167 to 89 against its introduction (Hansard, 21/7/1931, cols. 1249-58). Despite this set back for the eugenicists, in 1932, Wing Commander James, M.P. formed an all-party parliamentary sterilisation committee comprising of ten members of parliament. They adopted the Bill, which had been introduced by Major Church the previous year. The parliamentary committee produced a memorandum setting out their beliefs that, *inter alia*, 'mental defect' was hereditary, that sterilisation should be an adjunct to segregation, and that no 'defective' should become a parent. However, by the time their memorandum was published in November 1932, the Brock Committee had already been appointed and the parliamentary committee decided not to press for action until the Brock Committee's report had been published (Blacker 1962).

In June 1932, after years of debate[19], the question of sterilisation was referred to a Departmental Committee on Sterilisation under the chairmanship of Lawrence Brock. The committee concluded their work in December 1933 and their report was published in January 1934. The Brock committee found that although heredity was not the only factor involved, it did play a large part in the causation of 'mental defect' and disorder. They further found that, whilst some mental disorders could be aggravated by sterilisation, in the case of 'mental defectives' and 'normal persons' there was no evidence to demonstrate that sterilisation was psychologically or physiologically harmful. Although they acknowledged that sterilisation could aggravate some mental illness they discounted this due to their finding that the psychological advantages of voluntary sterilisation outweighed any possible disadvantages. They concluded that compulsory sterilisation was not justifiable. However, they recommended that voluntary sterilisation should be legalised subject to the approval of the Minister of Health on the recommendation of two doctors in each case.

Following the publication of the report there were numerous calls in parliament for its recommendations to be introduced into legislation. Support for these came from various disparate groups including the *Mental Hospitals Association*, the *Central Association for Mental Welfare*, the *Royal College of Physicians*, the *County Councils Association*, the *Association of Municipal Corporations*, the *Mental Hospital Matrons' Association*, a variety of women's groups, and organisations for the blind. Given that the 1913 Act had imposed a considerable financial burden on local authorities, it is not surprising that local authorities associations supported the introduction of sterilisation, as it was seen to be a more cost-effective means of preventing procreation than segregation. Surprisingly, the *Church of England Advisory Board for Moral Welfare* stated that there was no moral principle that would compel it to oppose legislation drafted along the lines of the Brock Report [Blacker, 1962 #101; Hansard, 13/4/1937, col. 827-829]. The Roman Catholic Church, however, vigorously opposed the legalisation of sterilisation [Cammack, 1938 #20; Hansard, 13/4/1937, col. 825]. In

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[19] Between February 1926 and June 1932 the question of sterilisation of 'mental defectives' was raised on fourteen different occasions and that of the prohibition of marriage on five occasions.

the same year that the report was published, the German National Socialist government passed legislation legalising both voluntary and compulsory sterilisation. Eugenic courts were set up and given the task of determining who should be compulsorily sterilised. People in England and Wales were concerned that such a system should not be introduced into the country and public opinion turned against the recommendations contained in the Brock Report (Blacker 1961; Blacker 1962). After April 1937 no further calls for the sterilisation of people with learning disabilities were made in parliament.

Even prior to World War II, attitudes towards eugenic sterilisation appeared to be diminishing. This was partly due to the fact that there was a swing from Neo-Malthusian policies to pro-natalist ones as a result of a de-population scare, which was heightened by the Depression of the 1920s (Blacker 1950; Kevles 1998). However, it was not until after the end of the war when the full extent of the Nazi atrocities became known, that people in America and England began to see eugenic sterilisation as unacceptable (Searle 1976; Jones 1980; Dowbriggen 1997; Kevles 1998). However, despite the fact that sterilisation was generally seen as unacceptable, in America sterilisation continued in a number of states throughout the early 1960s and in Alberta until as recently as 1972.

1.3.4.f. The working of the 1913 Mental Deficiency Act:

As stated earlier, the 1913 Mental Deficiency Act (as amended) not only provided for the institutionalisation of the 'mentally defective', but also provided for their guardianship, for their release from institutions on licence, and for statutory and voluntary supervision. What is not clear is how the Act worked in practice. Historical accounts, until recently, have generally focused on the institution and ignored community care, stating, either categorically or by implication that community care did not exist in any real form until the advent of the 1959 Mental Health Act. They also have a tendency to suggest that community care is preferable to institutional care. It is true that there was considerable growth in the number of institutions for people with learning disabilities and a dramatic increase in the number of people maintained in such institutions after the 1913 Mental Deficiency Act came into force. However, recent writers argue that the portrayal of learning disability provision as being essentially institutional is false, or at least only partially true (Bartlett and Wright 1999; Walmsley and Rolph 2001). Such writers make a number of points. Firstly, they note that despite the introduction of the Act the family continued to be the main care provider. Secondly, they argue that community care existed as an adjunct to institutional care rather than as an alternative. Thirdly, they argue that where people with learning disabilities remained at home they were subject to regulation and control as a result of licensing, guardianship, supervision and, from 1927, occupation centres (Walmsley, Atkinson et al. 1999).

Although little is known about the working of the Act, It has been argued that the legislation was not imposed by the Central Board of Control. Rather, there was considerable negotiation between the Board of Control, local authorities, who were responsible for ascertaining and caring for 'defectives' in their area, and families (Walmsley, Atkinson et al. 1999; Walmsley and Rolph 2001). Walmsley et al (1999), whilst noting that community provision varied throughout England and Wales, state that in Somerset there was a, *"...sophisticated array of provisions for ascertained 'mental defectives'"* (1999:190). Such provision included local authority run day and boarding schools, Occupation Centres run by the *Association for Mental Welfare*, arrangements for the voluntary and statutory supervision of 'mental defectives' living at home and licensing and guardianship schemes that were supervised by the local authority. Such schemes whilst cheaper than institutionalisation still enabled authorities to ensure that 'mental defectives' and their families came under their control. It has also been argued that when people were institutionalised this was not necessarily on a long-term basis and many individuals left institutions on licence or under guardianship orders. Welshman (1999) notes similar mixed provision in Leicester where, although there were a number of occupation centres and hostels, most people with learning disabilities were expected to return to their families for care in the evenings. Likewise, Jones (1960) also makes reference to Occupation Centres, noting that there was a growth in their number from 1922 onwards, thus suggesting that charities and local authorities were not exclusively concerned with institutional care. That community care was important throughout the period in question is made clear by O'Conner & Tizard (1956). They note that in 1916, there were 6,612 patients in institutions and 136 on guardianship orders throughout England and Wales. In 1951 there were 57,661 in institutions and 3,394 on guardianship orders. However, there were an additional 50,049 persons living in the community receiving statutory supervision.

One of the main concerns of eugenicists was that the 'mentally deficient' should not procreate. It would appear that this concern was reflected in the reasons why people were placed in strictly segregated institutions (Gladstone 1996). For example, Morris (1969) posits the view that a number of people were institutionalised as a result of their sexual promiscuity. Cox (1996), who reviewed case studies of girls certified under the Mental Deficiency Act and sent to industrial schools states that although few girls went before the juvenile courts on sexually related charges the way in which they were dealt with was influenced by their sexual histories. Likewise, Thomson, (1996) in his study of case files from London County Council notes that the Mental Deficiency Act was used to target sexually active females. However, Walmsley et al (1999) report that the evidence in Somerset demonstrates that the prevention of procreation was not the only concern; rather, there was a wider interest in controlling sexuality generally. They refer to people losing their licences or being institutionalised for such things as 'homosexual practices', 'associating with the opposite sex', and for 'talking to a schoolgirl'. They argue that these concerns about sexuality continued throughout the 1930s and 1940s and are evidenced in people's casenotes and on guardianship orders. Walmsley's study of documents from a Bedfordshire Mental Deficiency Committee also supports this argument (Walmsley 2000). However, she also notes that other factors such as poverty, respectability and employability would also be considered relevant to the decision as to whether or not to institutionalise someone (Walmsley 2000). Although marriage of the 'feeble minded' was not directly prohibited, s.10 (2) of the 1913 Act provided that the guardian of a 'defective' had powers as if the person were under the age of fourteen years. A 'defective', whether male or female, under a guardianship order, would, therefore, have to obtain the permission of their guardian to marry. Whether or not guardians used their power to prevent marriage is unclear, but given the recorded concerns about sexuality it is highly probable.

The United States did not have a national law in relation to people with learning disabilities. However the history of the treatment of people with learning disabilities in America is in many ways similar to that in England. Although the number of people with learning disabilities who were institutionalised continued to grow from the 1920s until the early 1960s, there are numerous examples of people being released from institutions on parole or into 'family care', a system similar to the British 'boarding out' under the Poor Law. However, in America, attempts to increase community care faltered as a result of a lack of public interest, a continued public belief that people with learning disabilities were a menace that required controlling and a lack of funds as a result of the Depression (Wolfensberger 1975; Scheerenberger 1983; Switzky, Dudzinski et al. 1988). As in England during the same period, concerns about sexuality were also a major cause of institutionalisation in the United States. Fox (1978) notes that many men were institutionalised as a result of such reported behaviours as masturbation, sexual excess, homosexuality, 'crimes against nature' and for a history of syphilis. However, he also notes that many more women than men were institutionalised on the grounds of sexual promiscuity. Moreover, sterilisation was often a precondition of discharge to a community placement (Scheerenberger 1983).

1.3.5: 1954 – 1971: The call for de-institutionalisation

After a lack of discussion of learning disability and mental health for many years on February 19, 1954 there was a parliamentary debate on the care and treatment of the mentally ill. Jones (1972) suggests that this was the start of a 'revolution' in the care of people with mental health problems and learning disabilities that culminated in the enactment of the 1959 Mental Health Act.

Following the report of the Royal Commission on Mental Illness and Mental Deficiency, the Percy Commission, which sat between 1954 and 1957, a Mental Health Bill was introduced to parliament. When the Bill, which was to become the 1959 Mental Health Act, was outlined, it was stated that its main principle was to transfer mental health services from institutions to the community (Jones 1972). Whilst family care in the community had always been the main form of care provision for people with learning disabilities, the Act provided that people with learning disabilities should only be compulsorily detained in the interests of their own health and safety or where this was deemed necessary for the protection of others. It thus meant that many people with learning disabilities resident in hospitals could no longer be compulsorily detained (Jones 1960). However, despite the Hospital Plan of 1962 calling for an increase in community services and the closure of institutions (Bartlett and Sandland 2000), and the publication of critiques on institutional care such as Erving Goffman's *Asylums* (1962), little progress was made in the way of de-institutionalisation.

During the late 1960s, a number of reports were published that were quite critical of the learning disability hospitals (Wing 1979). For example, Hunt, (1969) although not critical of hospital staff, was highly critical of conditions within hospitals and called for the building of extensions or new learning disability hospitals to stop immediately and for the money to be used for a hostel building programme. Another such report was that of the study undertaken by Pauline Morris, which was published in 1969. Her study comprised a total of 3,038 patients of learning disability hospitals. Her main conclusion was that almost half of the adult patients in the sample spent the day on the wards without any activities, stimulation or training, which, she argued, resulted in them remaining in a state of dependency. She argued that there was a need to change public attitudes towards people with learning disabilities and decried the fact that despite the passage of the 1959 Mental Health Act, some ten years previously, the number of people with learning disabilities resident in hospitals had remained virtually static. Chapter eight of her book is of particular interest as it looks at life and relationships within the hospital. She notes that attitudes to sexual behaviour varied, however, few appeared positive. Whilst some hospital staff allowed men to have 'girlfriends' others stated that they would rather condone homosexuality than have male patients molesting females (1969:177). She also notes that female patients were rarely allowed to undertake 'male' activities such as gardening. Moreover, in most of the hospitals in the study, staff had a strict attitude towards segregation and the sexes were not encouraged to mix (Morris 1969: p.180).

As well as such reports, there were a number of high profile enquiries into learning disability hospitals such as Ely and Farleigh in 1968 (Jones 1972; Heaton-Ward 1977). In the summer of 1970, R.H. Crossman, then Secretary of State for Social Services made a number of visits to hospitals to ascertain conditions within them. He found that they were understaffed, over-crowded and poorly provided for (Jones 1972). It was following this that the subject of learning disability once again came to the fore and the government produced a white paper, *Better Services for the Mentally Handicapped* (Department of Health and Social Services and the Welsh Office 1971). In the same year the *Campaign for the Mentally Handicapped* organisation was born and it started campaigning for the introduction of the 'normalisation' principle in England and Wales (Heaton-

Ward 1977). Since that time the process of de-institutionalisation has continued to unfold (Tomlinson 1991).

In America, the move towards de-institutionalisation came slightly earlier than in England and started with the development of national parent organisations such as the *National Association of Retarded Citizens* (NARC) which was created in 1950 (Scheerenberger 1983). Such organisations, as well as offering support to parents and organising locally based projects, also called for positive legislation. Such legislation was enacted during the Kennedy administration (1961-3). At this time, federal resources were made available for people with learning disabilities. Additionally there was the introduction of new philosophies such as 'rights based' models of care and the 'developmental model' which perceived people with learning disabilities as individuals who could benefit from education and training. In addition to the introduction of 'rights based' models and the 'developmental model' the principle of 'normalisation' was imported to America.

This principle had first been introduced in Denmark and was concerned with letting learning-disabled individuals exist in living conditions that were as close to 'normal' as possible (Carnaby 2002). The idea was then further developed in Denmark, Norway and Sweden during the 1960s where emphasis was placed on making available, to people with learning disabilities, the patterns and conditions of everyday life that were available to the mainstream or 'normal' population (Nirje 1973). This concept was then imported to America (Scheerenberger 1983; Switzky, Dudzinski et al. 1988) where it became re-defined by Wolfensberger, a sociologist. He framed the concept somewhat differently to the way it had been developed in Scandanavia (Barr 1995). He referred to it as the,
"*...utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible*" (Wolfensberger 1972).
Thus emphasis was placed on people with learning disabilities undertaking 'socially valued roles'. This was in an attempt to change the way in which society viewed and portrayed people with learning disabilities from being negative to more positive (Carnaby 2002).

1.3.6. Summary and Discussion:

From the above literature, whilst information is sparse, it is evident that the early history of people with learning disabilities was very mixed. Public attitudes towards people with learning disabilities varied both from time to time and place to place. At times public attitude was positive at other times negative. However most of the time public attitudes appeared to be neutral or apathetic and people with learning disabilities were treated in similar ways to the rest of the indigent. Such attitudes were shaped by a variety of factors. There are a number of factors that recur through the literature. One of these relates to belief systems, for example a belief in the supernatural. A second is the issue of economics. That is to say that it is reported that in times of, what would now be referred to as recession, people with learning disabilities, along with others who were unable to contribute to the economy, were disvalued and seen as a burden on the remainder of society.

From the sixteenth century onwards, however, the apparent apathy towards people with learning disabilities was replaced with a hostile view. People with learning disabilities became perceived as evil or the products of sin and it was believed that harsh treatment would 'drive the devil out of them'. At the same time they were also seen as subhuman or analogous with wild beasts in need of taming. As a result of this view, those that ended up in institutions were treated harshly.

It was not until the turn of the nineteenth-century that a belief developed that people with learning disabilities could be educated into becoming useful members of society. The first schools for the learning disabled were started in England and Wales during the mid-nineteenth-century. The development of such schools and the attitudes on which they were based were not unusual for the era as during the eighteen-thirties and eighteen-forties considerable amounts of legislation were passed with the aim of improving society. We can thus see the nineteenth century as a period when people with learning disabilities were clearly differentiated from people with mental health problems and a period in which progress was made in relation to their care and education.

However, within quarter of a century of the development of such schools, there was considerable concern expressed, predominantly by the professional classes, about the perceived rising level of degeneracy. From 1890, people with learning disabilities came to be a major focus of this concern. The reasons for the attribution of the increase in degeneracy to people with learning disabilities, whilst complex, are the result of a number of disparate factors. They include the move from an agrarian to an urban and capitalist economy, and the subsequent move from a society based on superstition to one based on 'scientific' fact. Other factors include social improvements, and improvements in medical knowledge and skill. Additionally there was widespread adoption of such phenomena as Social Darwinism, neo-Malthusianism, intelligence testing, eugenics and the re-discovery of Mendelian Law. At the same time, the medical profession was emerging as the new 'expert' in such matters. It is widely regarded that the 'promotion' of mental disorders, including learning disability as an aspect of degeneracy, the treatment of which required specialist skills, served the interests of the newly emerging profession of 'mad-doctoring'. Additionally, in the United Kingdom, there was a concern that the strength of the country over its dominions was threatened due to a perceived weakening of the British race.

Many organisations appear to have been concerned about the issue of degeneracy, and supported the calls for the segregation of people with learning disabilities. However, introduction of legislation was essentially the result of the persistent lobbying of a number of individuals such as Hume Pinsent and a few organisations such as the *Eugenics Society.* These individuals and organisations had a tendency to portray 'feeble-mindedness' as a hereditary organic disease and played on people's concerns about such things as law and order, poverty, declining imperial strength and racial degeneration whilst at the same time promoting their 'solutions' as cost saving.

Whilst solutions to the perceived 'problem' were wide ranging, the English and Welsh legislature chose to promote increased control over the sexuality of people with learning disabilities. They sought to achieve this through the introduction of the 1913 Mental Deficiency Act which provided both for the segregation of people with learning disabilities in institutions and for their control in the community through the means of licences, guardianship orders and from 1922 through Occupation Centres.

Interestingly even at the height of the 'eugenic scare' with its calls for the sterilisation of people with learning disabilities, the movement towards improved education for people with learning disabilities continued. This can be seen in the 1899 Education Act, the 1914 Elementary Education (Defective and Epileptic Children) Act and in the Wood Report of 1929.

Little is written about the working of the 1913 Act, though that which is available suggests that people with learning disabilities continued to be seen as lacking in value. For example, it was seen as important that they should be taken out of the employment they had undertaken successfully during periods of war in order that the 'more valued' returning service personnel could have work. It also appears relatively clear that the expression of sexuality was an important factor in deciding whether people with learning disabilities should be allowed to remain in the community or should be brought under the closer supervision and strict segregation of the institution. Despite increases in medical knowledge and genetics and the realisation that few forms of learning disability were inherited, no real attempt was made to reintegrate institutionalised persons with learning disabilities into their communities until 1971. This followed the publication of *Better Services for the Mentally Handicapped* (Department of Health and Social Services and the Welsh Office 1971) and the United Nations *Declaration of General and Special Rights of the Mentally Handicapped* (United Nations General Assembly 1971). Even at this time, it would appear that people's attitudes towards the expression of sexuality by people with learning disabilities was negative as can be seen from the study undertaken by Morris (1969) and from text books of the era.

The next section of this literature review considers the way in which alternative perceptions of the sexuality of people with learning disabilities have developed since 1971.

1.4 The development of the current discourse about men and women with learning disabilities and their sexuality: 1970 - present day

1.4.1. Introduction

People with learning disabilities are not generally regarded as a high priority by government. However, when they have been considered by government, policy documents and recommendations have built on the principles of the 1959 Mental

Health Act and the 1971 white paper, *Better Services for the Mentally Handicapped* (Department of Health and Social Services and the Welsh Office 1971). A recent example of such a policy document in England is *Valuing People* (Department of Health 2001). In Wales, since 1983, learning disability services have been based on the *All Wales Strategy* (Welsh Office 1983) although the Welsh equivalent to *Valuing People*, *Fulfilling the Promises* (National Assembly for Wales 2001) was recently published as a consultation document. In addition to the publication of policy documents, legislation such as the Community Care Act 1990 has come into force (Gilbert 1985; Walmsley and Rolph 2001). Such documents and legislation are generally based on the principles of normalisation and emphasise the need for service providers to enable individuals to achieve independence and control over their lives to as great an extent as possible (Walmsley and Rolph 2001).

As stated in section 1.4.5, the 1970s witnessed widespread uptake of the normalisation principle, first promulgated by Bengt Nirje during the 1960s (Perrin and Nirje 1989), so much so, that its goals have been described as being synonymous with those of community care (Chappell 1992). Additionally there was a growing recognition that people with learning disabilities had the same rights as non-learning-disabled people. Individuals with learning disabilities, who had previously been cared for and educated by Health Authorities, began to be reintegrated into the community and provided for by generic services. For example, the 1970 Education Act resulted in children with learning disabilities being returned to mainstream education in so far as local education authorities became responsible for their schooling as of April 1971. Additionally, local authorities began to take over from the health service as the main providers of residential accommodation for people with learning disabilities not living independently or with their families, though much of this provision has since been contracted out to voluntary organisations.

Nirje's definition of normalisation specifically discussed a move from segregated environments to 'bisexual' (sic) ones. He also discussed the marriage of people with learning disabilities as a means of alleviating loneliness (Nirje 1973). In line with this, a number of workers in the field of learning disability saw the expression of sexuality as an aspect of normalisation (Mulhern 1975; Rosen, Clark et al. 1977). Some enlightened service providers put this belief into practice. For example, although few and far between, some provided accommodation for married couples as early as 1973 (Sedgwick 1982).

In addition to the influence of normalisation, the fact that the United Nations (United Nations General Assembly 1971) had stated that people with learning disabilities had the same rights as other human beings resulted in some workers holding the view that the expression of sexuality was a right of people with learning disabilities (Craft and Brown 1994). Additionally, one should not forget that during the latter half of the 1950s, the whole of the 1960s and the early 1970s what has been referred to as 'the sexual revolution' occurred. During this period attitudes to a variety of aspects of sexuality such as abortion, divorce and birth control became more relaxed (Kempton and Kahn 1991; Downs and Craft 1996; Heath 2002). Given such phenomena it is hardly surprising that sexuality also became an issue of debate in relation to people with learning disabilities (Chapman and Pitceathly 1985).

However, whilst considerable achievements have been realised in relation to de-institutionalisation and re-integration into the community since 1971, there does not appear to have been similar progress in relation to the facilitation of expression of sexuality by people with learning disabilities (cf. Timmers, DuCharme et al. 1981; Brantlinger 1983; Brown 1994; Katz, Shemesh et al. 2000). Rather, the expression of sexuality by men and women with learning disabilities remains a controversial subject. This section reviews the results of studies relating to general attitudes towards the expression of sexuality by men and women with learning disabilities. It then reviews the findings of studies appertaining to the attitudes of carers to the sexual expression of men and women with learning disabilities. It continues by reviewing studies of the attitudes of women and men with learning disabilities towards sexuality including such things as self-image. In addition to considering studies of particular groups' attitudes, this section reviews the wider literature on learning disability and sexuality in an attempt to obtain a more accurate overview of attitudes towards the expression of sexuality by people with learning disabilities. The section concludes with a summary and discussion.

1.4.2. General Attitudes towards the expression of sexuality by men and women with learning disabilities.

Very few studies have sought to ascertain the attitudes of the general public towards the expression of sexuality by people with learning disabilities. This is somewhat surprising given that public attitude is often cited as a reason why the expression of sexuality by people with learning disabilities is perceived negatively. For example, Adams et al (1982) noted that one of the reasons for discussing sexuality was the community's fear that people with learning disabilities would commit sexual offences if returned to the community. Likewise, Dawson (1993) and Kempton (1991) reported that the public were concerned that the sexual urges of people with learning disabilities should be controlled if they were going to live in the community.

Block (2000), rather than surveying people to determine their attitudes, considers the ways in which women with learning disabilities have been portrayed in the United States both in non-fiction and fiction. Three of the case studies she considers are post 1970. She looks firstly at the 'Glen Ridge' sexual assault of 1989, where a young woman with a learning disability was sexually assaulted by a number of young men who were fellow pupils at her high school. Three of the young men were later tried for the alleged assault in 1992. During the trial, the defence lawyer criticised the young woman's mother for failing to protect the defendants from her daughter. Neighbours spoke of her as a succubus and a psychiatrist confirmed that the image portrayed of her being a threat to young men was correct. Block posits the view that such attitudes are directly attributable to past eugenic attitudes. The next case study she considers relates to the sterilisation of a woman with learning disabilities in 1994 following a seven year legal battle on the part of the woman's mother who sought the sterilisation on the grounds that her, '*...daughter might be raped and become pregnant*' (Block 2000, p.247). Here, in similar vein to her assertion in relation to the 'Glen Ridge' case she asserts that the sterilisation was only able to take place as a result of the legacy of the eugenics movement. The final case study concerns the 1998 film *The Other Sister*. In the film, a woman with a learning disability who had been institutionalised by her wealthy parents leaves the institution to return home. She then goes to college, obtains her own apartment, falls in love, marries and ultimately succeeds at everything she wished to achieve. The only barrier that slows her success is her mother's overprotective and controlling attitude. The movie may be seen as presenting the view that people with disabilities have the same aspirations as other Americans. However, Block argues that the film fails to acknowledge the numerous financial, interpersonal, social, educational and sexual barriers that are faced by people with learning disabilities living in the real world. Block concludes her review of the case studies by arguing that viewing people with learning disabilities as 'infantile', 'sexual monsters' and by ignoring their reality results in the perpetuation of abuse.

A more traditional study of attitudes was undertaken by Scotti et al (1996). They studied one hundred and thirty-five students who were enrolled on psychology courses at a university in south eastern America. The overall findings of the study were that the students viewed sexual behaviours as less acceptable when they were engaged in by people with learning disabilities than they did when those same behaviours were engaged in by university students. They did, however, find that where students had reported positive interactions with people with learning disabilities they were more positive about their sexuality.

More recently, Katz et al (2000) compared the attitudes of one hundred and thirty-five Israeli university students towards the sexuality of people with learning disabilities and people with hemiplegia. They found that the students recognised that both people with learning disabilities and hemiplegia had sexual needs. However, they also found that the students held more negative attitudes towards the sexuality of people with learning disabilities than they did towards people with hemiplegia. A further finding was that the students felt that people with learning disabilities had less right to personal choice than people with hemiplegia.

In addition to the above studies, concerned specifically with attitudes towards the expression of sexuality by people with learning disabilities, studies of general attitudes to people with learning disabilities are also relevant. That is to say that if people with learning disabilities are generally regarded in a positive light it is more likely that their expressing their sexuality will be regarded as acceptable.

A number of studies were carried out during the 1970s when children with learning disabilities began to be integrated into 'mainstream' schools. One such study is that of Gottleib and Corman (1975). Four hundred and thirty adults living in the Boston area were asked to complete questionnaires. A large majority of respondents demonstrated some accepting attitudes towards children with learning disabilities. However, older respondents, respondents who had children of school age, and those who had no or little previous contact with people with learning disabilities had the least positive attitudes and favoured segregation of children with learning disabilities.

Gibbons, et al (1979) undertook a study into the effect of labelling people 'mentally retarded'. The study was of eighty American psychology students. Participants were presented with a 'transcript' supposedly obtained from an interview with a seventeen-year old girl. The first page of the 'transcripts' either contained the label 'educable mental retarded' or no label. Participants were then asked a number of questions. The results showed that where a person was labelled as 'mentally retarded' they were not expected to have much control over their lives, and were seen as unable to make progress even if they exerted considerable effort. They were also perceived as being less likely to succeed in employment, marriage and parenting than someone not labelled 'mentally retarded'. They concluded that people with learning disabilities were not expected to succeed in life, but that if they did this was the result of external factors over which the person with the learning disability had little control (Gibbons and Sawin 1979).

Rees, et al (1991), undertook another study of students. They replicated a study originally conducted in 1975. One hundred and ninety-one Canadian students took part in the study. The conclusion of Rees et al was that, during the thirteen year period between 1975 and 1988, attitudes had become more favourable towards people with learning disabilities. They also found that increased contact with people with learning disabilities resulted in improved attitudes.

Another recent study of students' attitudes was that undertaken by Rimmerman et al (2000). This study was of one hundred and thirty-nine students at Bar Ilan University in Israel. Forty-four percent of the students tutored children with learning disabilities and the remaining fifty six percent of students tutored other children. They concluded that the association between contact and attitudes was dependent upon the time and length of exposure, with students who had had the longest contact with people with learning disabilities showing the most positive attitudes (Rimmerman, Hozmi et al. 2000). This lends support to the earlier finding of Selter and Litchfield (1984) that community opposition to community residences for people with learning disabilities diminishes considerably after residents had moved in and the local community had made contact with the individuals with learning disability. A similar study in the United Kingdom also found that the most positive attitudes were expressed by people living in the proximity of the most long established group home in the area (Pittock and Potts 1988).

Bromfield et al (1986) undertook a study of four hundred and twenty-five American school children aged between the years of eight and fifteen. They found that the sample were generally positive in their attitudes towards children labelled 'mentally retarded'. For example, they saw them as being desirable as a friend. Additionally failure of 'mentally retarded' children to achieve was less likely to be blamed on a lack of effort than failure of a 'non-retarded' child.

Another study of American school children was undertaken by Goodman (1989). One hundred and five children aged eight years were interviewed. They were given a vignette about a child a year younger than themselves who couldn't read or count and didn't understand the rules of games. The interviewees were asked to comment on the child and such things as whether he or she would catch up. The interviewees saw children they considered both 'smart' or 'dumb' as able to change if they made an effort. However, they saw 'mental retardation' as immutable and did not think that such children should be in 'mainstream' classes. However, their views of 'mentally retarded' children were not wholly negative, for example, they also stated that 'retarded' children could be pretty and athletic (Goodman 1989).

The results of such studies are clearly mixed although there appears to have been a move towards more tolerant attitudes over time. However, whilst this may be the case, it is arguable that attitudes towards people with learning disabilities continue on the whole to be negative. This has in particular been highlighted following the advances made by the Human Genome Project (Kuna 2001).

1.4.3. A discussion of learning-disability specific academic literature concerning people with learning disabilities over the period in question.

Although there is a paucity of studies specifically relating to attitudes towards the expression of sexuality if one looks at literature published over the period in question, one can gain an impression of the attitudes prevalent at the time of writing. One can also ascertain which issues relating to sexuality were seen as important.

During the 1960s it continued to be the case that pregnancy outside of wedlock might result in institutionalisation (Hilliard and Kirman 1965). However, academic writers, at least, became more amenable to the idea of people with learning disabilities marrying (Hilliard and Kirman 1965).

During the 1960s and early 1970s a number of studies were undertaken on marriage and people with learning disabilities by people such as Andron and Sturm (1973) Craft (1979), Edgerton (1993) and Mattinson (1970). In most studies the majority of marriages were seen both as beneficial to the people concerned and as successful in the eyes of the researcher. Throughout the 1960s and 1970s, no doubt partly as a result of such studies, marriage, preferably without children, was seen as the most preferred form of relationship for people with learning disabilities (Bass 1963; Oliver, Simon et al. 1973; Heaton-Ward 1977; Rosen, Clark et al. 1977; Craft and Craft 1978; Craft and Craft 1979; Wing and Gould 1979).

During the 1970s, there was considerably more discussion of sexuality and people with learning disabilities in publications than had previously been the case, e.g. (Tredgold and Soddy 1970; Craft and Craft 1978; Craft and Craft 1979; Wing and Gould 1979). During the first half of the decade such discussion, for the most part, recognised a need to discuss sexuality with people with learning disabilities. However, this was mainly from a biological viewpoint and little of the discourse was concerned with such things as intimacy and relationships. Moreover there was little interest shown in what people with learning disabilities themselves thought or felt about their sexuality. Rather, people with learning disabilities continued to be seen as 'abnormal' with the result that they continued to be denied the right to express their sexuality (Heshusius 1982). Much of the discussion had the aim of preventing relationships (Johnson 1987; Sinason 1992) and pregnancy (Kempton and Kahn 1991). The following quote from Kirman is not atypical of views of the first half of the decade, "*It is just as important for instruction in sexual matters to be included in the school curriculum for the mentally handicapped as those of normal intelligence. The explanations should however be simple and forthright ... Attempts should be made to avoid idealisation of marriage and childbearing, with emphasis on the realities and chores of family life.*' (Kirman 1975, p. 157).

During the second half of the decade sexuality began to be seen in more than behavioural or biological terms, as can be seen in such texts as Rosen et al (1977), Skelton and Greenland (1979) and Udall and Corbett (1979). That is not to say that the expression of sexuality was not frequently seen as problematic (Wing and Gould 1979) or that it was widely approved. For example, although Heaton-Ward (1977) states that the purpose of hospital care is to enable the individual to develop to the maximum of their potential, leave hospital and live as independently as possible he appears unsure about the idea of individuals expressing their sexuality. For example he states that, "...mentally handicapped men and women *may* have a right to love..." (Heaton-Ward 1977, p.135) but then suggests that such individuals are not capable of parenting and that females of 'child-bearing age' should be fitted with contraceptive devices. Elsewhere in the book he speaks disapprovingly of the possibility of 'mildly mentally handicapped' women conceiving unwanted children (Heaton-Ward 1977, p. 36). He does not even appear to consider the possibility that the children may be wanted.

In addition to parenting by people with learning disabilities being seen as unacceptable homosexual relationships remained taboo (Kirman 1975) as the following quotation demonstrates:

"*It is important that houseparents understand that homosexual behaviours should not be condoned, and that they are expected to discourage, prevent, and vocally disapprove of such activity. Furthermore, they must be made to understand that such behaviours are reversible.*" (Rosen, Clark et al. 1977, p.270).

The author then went on to recommend aversion therapy for homosexuals, despite having a few pages previously recommended that sex education programmes should attempt to undo,

'*... anxiety and inhibition in relation to sexual responsiveness*' (Rosen, Clark et al. 1977, p.266).

During the 1980s, issues relating to the sexuality of people with learning disabilities were more widely discussed than many other aspects relating to sexuality. For example, it was the second most frequently discussed topic relating to sexuality in the '*Nursing Times*' during the decade (Carr 1996). Despite the fact that the sexuality of people with learning disabilities often continued to be suppressed (Murphy, Coleman et al. 1983; Craft and Craft 1985), a considerable number of texts solely concerned with sexuality and people with learning disabilities, such as "*Sex education and counselling for mentally handicapped people*" (Craft and Craft 1983); "*Sexuality and mental handicap*" (Dixon 1988); *and "Sex education for persons with disabilities that hinder learning*" (Kempton 1988) were published.

Additionally, general texts on learning disability, particularly those published in the latter half of the decade, tended to be more positive about the issue of sexuality. For example in his book '*Mentally handicapped people: living and learning*', which was used as a core text for student nurses, Clarke (1986) argued that if we accept the principle of normalisation, we have to accept that people with learning disabilities have the same sexual rights as other people and that they should be, 'helped to achieve satisfying emotional relationships,' (Clarke 1986, p 202). Other writers, such as Jenkins, discussed sexuality as being an important aspect of an individual's transition to adulthood (1989). However, although attitudes towards the sexuality of people with learning disabilities were generally more liberal, homosexual behaviour continued to be regarded as 'unacceptable behaviour' (Shanley 1986, p124).

From the mid 1970s and throughout the 1980s one of the main themes of discussion was the vulnerability of clients to sexual abuse, combined with a growing recognition that levels of abuse were higher amongst people with learning disabilities than they were amongst the general population (Johnson 1984) (Skelton and Greenland 1979).

Towards the end of the 1980s an issue that became a major discussion point was sterilisation. This was as a result of the case of In re F (1990) 2 AC 1. In this case, the mother of a 36 year old woman with a learning disability sought a declaration from the court that sterilisation would not be unlawful due to the absence of F's consent. The judge who heard the case at first instance, the Court of Appeal and a House of Lords judicial appeal committee all agreed that it was appropriate for such a declaration to be granted, though the House of Lords required that High Court declarations should always be sought in such cases.

A further issue that was focused on throughout the 1980s was that of men with learning disabilities who committed sex offences (Kempton and Kahn 1991). This issue remains topical today (Wheeler and Jenkins 2004) and a number of authors such as Lindsey have undertaken considerable work in the area, (e.g. O'Conner and Rose 1997; Lindsay, Marshall et al. 1998; Thompson and Brown 1998)).

During the 1990s, the abuse of people with learning disabilities continued to be one of the main themes of discussion in relation to the sexuality of people with learning disabilities, e.g.: (Sobsey 1994; Sundrum and Stavis 1994). Despite this, in a study of one hundred and seven staff working in day services and residential settings, Allington (1992) found that almost a third of the staff stated that they never discussed such issues in the workplace.

Other topics also emerged in the literature as major themes. They included HIV / AIDS (McCarthy and Thompson 1994; Cambridge 1996; Scotti, Ujcich et al. 1996) and parenting by people with learning disabilities (Feldman 1994; McGaw 1997; Sheerin 1998; Baroff and Olley 1999), both of which were seen as issues of growing concern. A concern that had occasionally been present previously (see Shapiro and Sheridan 1985)), but which became more widely discussed during the late 1990s and currently remains important is that of sexual health. Whilst this encompasses things such as sexually transmitted infections, HIV and AIDS, it also includes access to services such as smear testing (Brown 1997; Nightingale 2000; Servais, Jacques et al. 2002).

We can see from the above literature that whilst issues relating to the sexuality of people with learning disabilities have been discussed for over three decades very little of the discussion was concerned with positive aspects of sexuality. Rather, much of the discussion focused on sexual behaviours that were considered to be unwanted or unacceptable, biological aspects of sexuality, issues that might be termed as the problematic, or negative aspects of sexuality such as abuse and infection (Haight and Fachting 1986; McCabe and Schreck 1992; Chivers and Mathieson 2000). A prime example of this can the 1997 JARID "special issue on sexuality"[20] where all six of the articles in the issue were related in some way to abuse. These concerns continue to dominate the literature on sexuality and people with learning disabilities. As a result of such concerns, rather than sexuality being seen as a positive aspect in the lives of people with learning disabilities it has been seen as a hazard or risk that needs to be overcome (Heyman and Huckle 1995; Manthorpe, Walsh et al. 1997; Collins and Cozens 1999).

However, there is also a small but growing quantity of literature that is concerned with such things as the views of people with learning disabilities, the relevance and importance of personal relationships and sexuality to their lives, and the possibility that the expression of sexuality may be a positive experience (Kempton and Kahn 1991).

1.4.4. Carers' attitudes towards the expression of sexuality by women and men with learning disabilities – A chronological review of the literature to date.

Quite a large number of studies into carers' attitudes towards the expression of sexuality by people with learning disabilities have been undertaken. Unfortunately their results tend to be contradictory (McCabe 1993). This is due to such things as the size of samples, the lack of use of standardised research tools, and the fact that different countries have disparate laws and attitudes towards the expression of sexuality generally. For example, in Canada it is illegal to discriminate against people on the grounds that they are homosexual (Hingsburger 1993), whereas in the UK such discrimination is not unlawful other than in relation to employment. As a result of these factors the findings of such studies can rarely be compared with one another, nor can they be generalised.

The attitudes and behaviour of carers, both family and staff, are important due to the fact that most people with learning disabilities are either cared for or supervised to some extent. As a result of this people with learning disabilities may be unable to express their personal choice. Rather, they may be 'guided' in their choices and behaviour by their carers. Carers can thus be seen to have considerable personal influence or control over the sexual expression of those

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[20] (1997) **10** (2)

they care for (Saunders 1979; Chapman and Pitceathly 1985; Rose and Jones 1994; White and Barnitt 2000; Christian, Stinson et al. 2001; McConkey and Ryan 2001), particularly where they receive no guidance, for example from policies (Brantlinger 1983).

1.4.5. Attitudes of employed carers

One of the earliest studies undertaken during the period of consideration was that of Meyen and Retish (1971). They surveyed forty-two teachers from thirteen American states. All of the participants worked with people with learning disabilities and all were attending a two week workshop on sex education for the 'educable mentally retarded'. The authors measured participants' attitudes towards various aspects of dating. They found that teachers held conservative attitudes towards such behaviours.

Mulhern (1975) undertook a survey of sexual behaviours in eighty-two institutions in the United States. The survey also sought information on policies relating to sexual behaviours at each institution. He found that whilst 70% of respondents saw guidelines or policies as the best way of handling sexual behaviour amongst clients, only 23% of respondents stated that their institution had such policies. He notes that there was also a discrepancy between behaviours that superintendents of the institutions thought should be permitted and behaviours that were actually permitted. In the majority of cases, superintendents thought that behaviours that occurred should not be permitted although a sizeable minority felt that behaviours that weren't permitted should be. Mulhern also reports that 67% of respondents felt that sexual frustration was a significant factor in relation to most residents' problems of adjustment. However, he also reports that the only widely endorsed sexual behaviours were kissing briefly in private or public and masturbation in private.

One of the most widely cited studies into the attitudes of staff working in institutions to be carried out in the 1970s is that of Mitchell et al. (1978). This was a study of one hundred and seventeen members of staff employed in one of three institutions in Southern California. The study looked at a range of types of sexual behaviour in a variety of places. It was found that heterosexual behaviour was seen as more acceptable than homosexual behaviour, that all sexual behaviours were more acceptable when the couples engaging in them were alone rather than when others were present and that the bedroom was seen as the most appropriate place for sexual behaviour. However, a large number of staff felt that no sexual activity was appropriate for the people with learning disabilities resident in the institution they worked. Mitchell et al. also enquired as to whether staff felt that inappropriate sexual activity was occurring in their place of employment. A large percentage of staff responded that they did feel that inappropriate sexual behaviours were occurring and that as a consequence of this sex education and intervention programmes would be of value. Finally they noted that the attitudes displayed by staff towards the sexual expression of people with learning disabilities was more conservative than both academics' attitudes and than social norms current at the time.

Another study of the late 1970s is that undertaken by Saunders, who undertook a study of staff attitudes in four private residential facilities in two mid-western American states (Saunders 1979). Of the seventy-five respondents, 89% believed that people with learning disabilities had the same sexual drive as adults without learning disabilities. This ties in with the finding that 74% of the respondents felt that residents' knowledge of physiological aspects of sex was inadequate, as was their knowledge of the social dimensions and responsibilities of sexual relationships. All but one of the respondents thought that sex education was necessary for residents in their establishments and a majority (68%) did not think that sex education would incite residents to exhibit sexual behaviours. Other than in relation to homosexual activities, most staff expressed liberal views and a willingness to assist residents in coping with their sexual feelings[21]. Other findings of the study were that there was a perceived need for sexuality policies and education for staff around sexual issues. Despite over two decades having passed since this research was conducted, the same perceived need remains in existence today (McConkey and Ryan 2001).

Studies undertaken throughout the 1980s and 1990s suggest that a wide variety of factors shape carers' attitudes. For example older parents and care staff were generally found to be more conservative than younger carers (Brantlinger 1983).

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[21] It appears that during the 1980s homosexual behaviour was better tolerated in the UK than the USA Sweyn-Harvey, R. (1984). "Care staff attitudes to the sexuality of mentally handicapped hospital residents." Mental Handicap 12(1): 28-29.

Education was also seen as a factor influencing carers' attitudes. For example, Brantlinger (1983) found that graduates were considerably more liberal in their views than people who had a high school diploma or less. Cultural attributes and differences have also been regarded as an important influence on attitudes (Katoda 1993; Day and Harry 1999). A further possible influence is religious affiliation, with people with strong religious affiliations being seen as more conservative than those without religious affiliation (Wolf and Zarfas 1982; Brantlinger 1983; Lewis and Bor 1994; c.f. White 2002).

In addition to the above factors, some studies suggest that attitudes depend, at least to some extent, on whether the employed carers work in institutions or in community settings (Brantlinger 1983). Carers in institutional settings appear to be more conservative than those working in community settings. For example in their study of community and institutional based staff in two American states Adams et al. (1982) found that staff based in institutions showed less positive attitudes towards heterosexual behaviour amongst clients than community based staff. However their other findings did not appear to vary according to setting. For example, they found that all staff were more tolerant of sexual behaviours that occurred in private. Additionally, they showed a higher tolerance of heterosexual behaviour than homosexual behaviour. It also appeared that pregnancy was a concern of staff, as they were more tolerant of heterosexual intercourse when some form of contraception was used than when such behaviour occurred without contraception.

Not all studies support the idea that institution based staff are more conservative than community based staff. For example, Coleman and Murphy (1980) undertook a study of sexual attitudes and sex education in American institutions of fifty or more residents. They received questionnaires back from one hundred and thirty-one, or 40%, of the institutions they sent the questionnaires to. They found that the most frequent difficulty institutions found in administering sex education programmes was the adverse reaction of staff towards the expression of sexuality. Despite this staff attitudes were generally quite positive. It should, however, be noted that the survey was very limited in that it only sought attitudes in relation to four sexual activities. In relation to those activities they found that 88% of respondents either approved or strongly approved of masturbation, 72% approved or strongly approved of heterosexual petting, 56% approved of clients having sexual intercourse and 41% approved of clients exhibiting homosexual behaviour. They also found that 60% of respondents believed that people with learning disabilities should be able to marry and have children, though a number of respondents qualified this response. For example 8% of respondents who agreed with marriage stated that it should be contingent on sterilisation.

In New Zealand, Chapman and Pitceathly (1985) sought to survey twenty eight care staff. However, eleven of the staff who had at first agreed to participate in the study then failed to do so. The main reason given for this was that they felt that the issue of sexuality did not warrant systematic attention. This belief that sexuality is not particularly important is supported by the findings of Toomey (1993), who found that staff working in adult services in the Republic of Ireland ranked sexuality education as fourth out of a list of six activities[22].

However, of the seventeen staff that did participate, most of them recognised that people with learning disabilities had sexual feelings, ten responded that homosexual relationships were acceptable under some circumstances, thirteen stated that they would tolerate individual masturbation in private, and fourteen stated that heterosexual relationships between adults with learning disabilities were acceptable. However, none of the respondents agreed that sexual relationships should be encouraged, and nine out of the seventeen stated that involuntary sterilisation was acceptable. The results although mixed showed a trend towards conservatism.

Johnson and Davies (1989) undertook a study of the attitudes of two hundred and four staff all of whom were attending workshops on sexuality and learning disability. These workshops were held in a number of places including British Columbia and the United Kingdom. The staff tended to be most restrictive in relation to issues around homosexuality, involuntary sterilisation and mandatory pre-marital counselling. Generally, however, staff attitudes towards the sexuality of people with learning difficulties were not significantly different to their attitudes towards the sexuality of non-learning-disabled people.

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[22] Staff were asked to rank six 'day to day' activities in importance. They ranked them as follows: Self care 1st; work activity 2nd; social activity 3rd; sex education / counselling 4th; leisure activities 5th and domestic activities 6th.

Hingsburger (1993) undertook a survey of two hundred and thirty-one participants in sexuality workshops in Ontario, and one hundred and seventy participants at workshops in Louisiana and Texas. He found that staff attitudes in both Canada and the USA were more favourable to sex education and a variety of sexual behaviours than was the case in the study undertaken a decade previously by Coleman and Murphy (1980). Hingsburger acknowledges the fact that in his study the participants were attending sexuality workshops and as a result of this might not be representative of all carers nor comparable with Coleman and Murphy's study. However, this having been said, in both studies the ordering of behaviours from most acceptable to least acceptable had not changed. For example in both studies sex education was seen as highly acceptable, whilst the sexual behaviour found to be least acceptable was homosexuality.

Katoda (1993) undertook a study of parents and teachers of children with learning disabilities in Stockholm and Tokyo. Although, as a result of cultural differences, there were variations in the questionnaires used in the two countries, the contents of the questionnaires were as similar as possible. The study found that teachers in Stockholm taught more sex education, which was of a broader nature than their Tokyo counterparts. They also found that the Stockholm teachers expressed more liberal views about sex and interpersonal relationships than the teachers in Tokyo. Katoda suggests that the main reasons for the difference were that Sweden had a longer tradition of teaching about sex and personal relationships in schools, and that sexuality education is not compulsory in Japanese schools.

Murray et al. (1995) undertook a survey into staff attitudes towards client sexuality, AIDS and testing for HIV. The study was of staff employed by a single organisation that provided services to people with learning disabilities throughout the Greater Glasgow area. Of the four hundred and fifty employees invited to participate, two hundred and forty-six staff returned completed questionnaires. Respondents came from a variety of backgrounds such as nursing, occupational therapy, psychology, residential care and social work. They found that staff attitudes towards people with learning disabilities and AIDS were moderately positive, whilst their attitudes towards the sexuality of clients were highly liberal. However, the attitude to mandatory HIV testing was mixed, with 44.1% of direct care staff stating that there should be mandatory testing of people with learning disabilities for HIV whilst 40% disagreed with this view. They also found that staff attitudes towards the sexuality of clients were a highly significant predictor of attitudes towards people with learning disabilities and AIDS.

Another study of employees was undertaken by Murray et al. in 1999. This time the sample was drawn from employees from one of three organisations in one area in England, namely the NHS, Social Services and the private and voluntary sector (1999). Of the three hundred and thirty-two employees invited to participate, one hundred and seventy-eight people returned completed questionnaires. The study generally showed participants to have moderate to highly liberal attitudes, though direct care staff had less liberal attitudes than other participants. However, in relation to awareness of service policies concerning sexuality, the authors found that NHS staff were less familiar with their policies than social services staff. They also found that 56% of the survey participants reported that they were not influenced by policies in their interaction with clients. They posit the view that this may be due to the fact that sexuality policies tend to address the needs of the organisation rather than those of clients or staff. Alternatively, it may be the result of the contents of the policies lacking specificity, with the result that they can not be applied to real situations.

Christian et al (2001) undertook a study of the values of support staff towards the sexual expression of women with learning disabilities. The staff worked for a Californian agency that provided residential accommodation, education, supported employment and day services to people with learning disabilities. A comprehensive sexuality policy had been in place since 1990 and this had been updated annually. As with other studies, the results were somewhat mixed. For example, 90.7 % of the respondents agreed that the sexuality of a woman with a disability was an important part of who she was, however 44.2% of them felt that there were more important priorities to focus on in providing support services to women. In relation to reproduction, however, the responses reported in this study were more positive than earlier studies. For example, 83.7% of respondents supported the right of women with learning disabilities to have children, and 93% expressed the view that if given appropriate training and support, these women could be competent parents. Likewise, most of the respondents, (93%) thought that women with learning disabilities should receive sex education. Additionally 76% stated that they would feel comfortable supporting a woman in expressing her sexuality despite the fact that only 23.2% had received training in how to do this.

Hogg et al (2001) undertook a study of the attitudes of seventy-nine staff undertaking training on sexual abuse in Scotland. Attitudes were assessed both prior to and after completion of the course. They report that staff showed positive views towards the sexuality of people with learning disabilities and their right to sexuality education. However, like Hingsburger (1993), they acknowledge that as a result of participants having volunteered to undertake the training it is likely that they held more positive views than carers who did not volunteer and whose attitudes were thus not assessed in the study.

Recent studies generally suggest that staff hold more positive attitudes towards the expression of sexuality by people with learning disabilities than was the case in the past. Additionally it no longer appears the case that work setting has a role in shaping attitudes. For example, in her study of staff working in a secure unit for people with learning disabilities, Holmes (1998) found that staff attitudes towards the expression of sexuality by people with learning disabilities was generally liberal. However, she also found that some staff, particularly nurses, who are likely to have more influence on the residents behaviour than other groups of staff, were fairly conservative in their attitudes and were unreceptive to the idea of policy change (Holmes 1998, p. 114).

This more positive attitude of staff who care for people with learning disabilities on a regular basis is not visible amongst professionals who have irregular contact with clients, such as primary health care workers. Rather, the few studies that are available suggest that they hold attitudes that may be described as negative and conservative both in relation to people with learning disabilities generally and towards the idea of them being sexual beings.

Nightingale's report of her study (2000) clearly demonstrates the negative perception of people with learning disabilities held by many primary health care workers, despite guidance documents relating to the health care needs of people with learning disabilities having been produced for primary health care workers (Lindsey 1998; Lindsey and Russell 1999). Her study was concerned with cervical screening and involved the interviewing of general practitioners, practice nurses and practice managers in sixty-two general practices in one health authority in East Anglia. She found that some practices removed women from the cervical screening lists for reasons such as them being 'professional virgins'(such as nuns) or 'subnormal'. She also found that practitioners made assessments as to the appropriateness or otherwise of screening patients on subjective assessments. One example she gives of such subjectivity is that of a practice nurse who stated that a person with Downs Syndrome '*didn't look as though she was sexually active*' (Nightingale 2000, p. 28). Whilst she reports that some primary health care workers held positive attitudes towards the sexuality of people with learning disabilities, she found that the attitudes that emerged most frequently were that women with learning disabilities were 'child like', 'innocent', 'open to abuse' or 'non-sexually active'. Others saw them as irresponsible in their sexuality, promiscuous and in need of control.

1.4.6. Parental / family carers

Studies of parents' attitudes towards the sexuality of their children are less common than studies of staff attitudes. Like staff based in institutions, parents of people with learning disabilities are often regarded by professionals as holding negative views towards the sexual expression of individuals with learning disabilities.

Goodman et al (1971) interviewed the parents of fifteen adolescents who were 'educable retardates' known to the New York Medical College. The study was an exploratory one aimed at ascertaining whether parents provided their offspring with sexuality education or recognised the need for a structured sex education programme. They found that parents had made little, if any, effort at providing their learning-disabled offspring with any sex education. They also found that parents showed considerably more anxiety over sexuality issues in relation to their learning-disabled children than their non-learning-disabled children. All parents were concerned that their children might be sexually abused and as a result of this placed what the authors describe as 'excessive restrictions' on travel, friendships and activities. All expressed a hope that their children would marry 'a normal partner', however, the majority of parents of both males and females considered sterilisation.

Fischer and Krajicek (1974) undertook a study of sixteen children from a school in Denver and their parents. They found that most parents showed concern about the sexual development of their child. The main concerns of parents of females related to abuse, dating and pregnancy, whilst the main concern of parents of males related to abuse, homosexuality and masturbation.

Pueschel and Scola (1988) undertook a study in Rhode Island, USA, of the parents of seventy-three adolescents with Down's Syndrome. The parents were asked to complete a questionnaire concerning their child's social interaction, interest in the opposite sex, sexual function and sex education. They found that more than half of the parents reported that their child showed interest in the opposite sex, but that less than a quarter of them had boyfriends or girlfriends. They found that 53% of parents with sons and 43% of parents with daughters believed that they should be sterilised or be given birth control if they were capable of reproduction. However, a majority of parents (70%) stated that they would not feel uncomfortable talking to their child about sexual matters, though some did feel that their child would not understand the concepts involved in sexuality education. The other main finding was that parents were concerned that their son or daughter might be abused. Because of this, some parents reported telling their children to be wary whilst others did not allow their teenage child to be unsupervised at any time. Parents also showed considerable apprehension at the idea of their children having intimate relationships or getting married due to a belief that the young adult would not cope with the responsibilities and consequences of such a relationship. Others stated that they felt that the local community would react negatively if their children were sexually active.

Johnson and Davies (1989) in their study of staff (discussed in the previous section) also surveyed a group of twenty-eight parents, though their report does not state how they were selected. They found that, unlike the staff, the parents articulated significantly different attitudes towards the expression of sexuality by people with learning disabilities to the attitudes they articulated towards the expression of sexuality by non-learning-disabled people. They expressed the view that individuals with learning disabilities required more sex education, more pre-marital counselling and more access to abortion services than non-learning-disabled people. As with Heyman and Huckle (1995) Johnson and Davies found that parents were concerned that if their offspring became pregnant they would have to care for any children that resulted from the pregnancy. They felt that such concerns were pragmatic.

Katoda (1993) studied the attitudes of parents and teachers in Tokyo and Stockholm as discussed in the previous section. As with the attitudes of the teachers, the study found that Stockholm parents held more liberal attitudes than their Tokyo counterparts. However, whilst there was little significant difference between the attitudes of parents and teachers in Stockholm, there were a number of differences between the parents and teachers in Tokyo. Teachers there generally had more liberal attitudes than parents.

In her study of five families in Coventry, Dawson (1993) found that whilst parents recognised their offspring's sexual awareness most regarded it in child-like terms or described their childrens' attitude to sexuality as being unrealistic. She also found that all the families were against their offspring being given advice on homosexual relationships, a finding also made by Newens and McEwan (1995). Most parents were concerned about abuse and pregnancy and some were concerned about HIV and other sexually transmitted infections. A number of the parents had considered sterilisation for both male and female offspring. Finally, all parents expressed the view that it was right for them to exercise control over their son's or daughter's sexuality despite the fact that most of their children were over eighteen years of age.

Shepperdson (1995), undertook three studies of two cohorts of carers of young people with Down's Syndrome in South Wales during the period 1981 to 1990. It is not clear how many carers were interviewed due to the way in which the study is reported but it would appear to be between seventy-eight and one-hundred and four. Although sexuality was discussed in general terms with the carers, specific questions were asked about marriage, parenthood, extra-marital sex and sterilisation. Shepperdson reports that in 1981 although parents appeared to be understanding about their teenage children's sexual urges, they rarely encouraged them to express their sexuality and most used distraction or dissuasion as a means of dealing with sexual behaviour. When the same carers were interviewed in 1990 they were found to display more liberal attitudes towards the sexuality of their then adult offspring. For example, in 1990, more parents expressed the view that marriage was possible than had in 1981. This having been said, however, these parents were still relatively conservative in their views. For example, 71% were willing to consider the sterilisation of their offspring, and 85% did not agree that their adult child should become a parent. The reasons they gave for these views varied but included the perceived risk of abnormality in any baby, the inability of the person with Down's Syndrome to care for a baby, their reluctance to look after a grandchild, and because it would be stigmatising for a child to have a parent with Down's Syndrome. In relation to parents' attitudes towards sex education, parents originally interviewed in 1981 showed a more negative view towards it in 1990 than they had in 1981. Strangely, given their views on parenting, where they had provided sex education, more had provided information on pregnancy and birth than on sexual intercourse. A number of parents were wholly against sex education, for example, one mother stated of her son, "*I'd rather keep him chaste.*" (Shepperdson 1995, p.342), implying that if he did not know about sexuality it would not be an issue. Parents appeared to exercise considerable control over their teenage and adult children. For example Shepperdson reports that activities at clubs, schools, and day centres were closely supervised. Opportunities to build relationships were not nurtured and on occasions couples were split up. Shepperdson notes that restrictions on the expression of sexuality were not the only restrictions placed on the individuals with Down's Syndrome. Few were able to undertake other activities that are signifiers of the transition to adulthood, such as managing their own budgets or achieving some form of employment. This fact was also noted by Davies and Jenkins in their study of the way in which sixty young adults with learning disabilities residing in West Glamorgan perceived themselves (1997). Shepperdson portrays the carers as experiencing conflict. On the one hand they acknowledged the biological urges and sexual interests of their children and often encouraged their children to behave in a manner appropriate to their gender. On the other hand parents placed considerable controls over their adolescent and adult children with the result that none of them had what Shepperdson sees as a 'normal' close relationship with a person of the opposite sex which had a social as well as a sexual aspect.

Heyman and Huckle (1995) in their study of twenty adults with learning disabilities and their carers also found that parents generally held negative views towards their adult children expressing their sexuality. They expressed concerns about a number of issues including having to cope with abuse and possible consequences of sexual relationships, such as their breakdown, marriage and parenting. Because of these fears, parents only permitted their adult children to take limited risks which Heyman and Huckle compared with those that would be considered normal for pre-adolescent children (Heyman and Huckle 1995, p.141) However, Heyman and Huckle acknowledge that such fears are rational. They also found that some parents ascribed to myths such as that 'the sexuality of men with learning disabilities was dangerous', that 'they were childlike and thus asexual' or that they 'would not be able to restrain their behaviour so that it fell within that which was perceived as being socially acceptable'. Many of the parents in the study also felt that sex education should be avoided due to the fear that it would cause their child to want a sexual relationship. Those parents that did support the idea of their adult children receiving sexuality education did so only because it was seen as a way for them to avoid abuse.

All of the studies above relate to parents of children with mild to moderate learning disabilities. There are very few studies of the attitudes of parents of children with profound and multiple disabilities, in fact, the sexuality of such individuals is generally ignored (Downs and Craft 1996; Downs 1998). One of the few such studies reported is that of Swain and Thirlaway (1996). The study was of seven parents of children attending a school in northern England. Whilst the authors note that there is no such thing as 'a parental view', there were a number of commonalities. For example, the parents held a similar view of the meaning of 'sexuality', namely that it was defined in terms of overt sexual behaviours and feelings on the part of the young person with the disability. The central dilemma they report was one of parents having to decide whether or not to deny the young person's sexuality. Sexuality was seen as something that parents should consider, but was an issue that they had neither the time nor the energy to address. On the one hand, most parents felt that because their children had showed little or no signs of sexual awareness there was no reason to address issues of sexuality. On the other hand parents were forced to think about sexuality as a result of their child developing physically, especially in the case of females reaching the menarche. Swain and Thirlaway are sympathetic to the conflict that parents face and call upon formal carers to provide helpful responses to parents.

One of the few studies into the intimate relationships of people with learning disabilities that portrays both parents and staff as being either neutral or positive in their attitudes towards such relationships is White & Barnitts' study of eight individuals who attended a social club for people with learning disabilities in Hampshire (2000). Of those eight, seven had experienced some form of intimate heterosexual relationship. However, whilst the interviewees felt able to discuss the positive and negative aspects of their relationships with their carers, they did not feel able to discuss sexual activity with their parents.

In addition to the above studies looking at parents' attitudes towards the sexuality of their learning-disabled offspring a number of studies were undertaken in relation to parents' attitudes towards the sterilisation of their children. Such studies although not wholly demonstrative of parents' attitudes towards the expression of sexuality by their offspring do provide readers with a further insight into parents' attitudes towards parenting by people with learning disabilities. Some of these studies are now briefly reviewed.

Whitcraft and Jones (1974) undertook a survey of six hundred and fifty two individuals in Texas. Of the sample, three hundred and eight were parents. Of those parents, two hundred and sixty-nine approved of sterilisation. Most of these parents thought that their learning-disabled children would not be able to maintain a marriage or rear children successfully (Whitcraft and Jones 1974).

Wolf and Zarfas (1982) undertook a study of Canadian parents to ascertain their attitudes towards the sterilisation of their children. They sent out three hundred questionnaires and had one hundred and fifty-seven returned. 71% of the parents favoured involuntary sterilisation. There was no statistically significant difference between the attitudes of fathers and mothers, though more parents felt that females with learning disability should be sterilised than males. Additionally, a majority (64%) of parents did not see the need for a third party to intervene if they and their physician had agreed that sterilisation was appropriate for their offspring. Unlike Brantlinger (1983) Wolf and Zarfas found no association with religion and differing views in attitudes towards sterilisation.

Roy and Roy (1988) considered some of the ethical and moral issues concerning the sterilisation of women with learning disabilities residing in the West Midlands.

One of the questions they considered was why parents sought to have their children sterilised. They provide a number of reasons including, the belief that any child resulting from sexual intercourse would be handicapped, that the birth of a child to their handicapped child would be an economic and emotional burden, and that it may prevent sexual exploitation. A further reason given in favour of sterilisation was that parents believed that they would face considerable social stigma if their daughter were to become pregnant as the pregnancy would be attributed to their having failed to adequately supervise or control their daughter (Roy and Roy 1988).

Bambrick and Roberts (1991) undertook a postal survey of parents in Nottinghamshire. Questionnaires were distributed to two hundred and seventy four families. Of these, one hundred and thirty eight households responded. Although the age of the children in the survey ranged between 13 and 25 years, the majority (78%) fell within the 17 to 25 year old age range. 90% of the children were regarded as having severe learning disabilities. In relation to the parents' perception of their sons' or daughters' sexuality, less than one third of parents regarded them as showing an interest in the opposite sex. Additionally the majority felt their child lacked sufficient capacity for marriage or parenting and only 5% of parents thought their son or daughter to be capable of participating in any discussion on sterilisation. However, 53% of respondents said they had or would consider sterilisation for their child. Interestingly, given the fact that there has only been one reported application to the United Kingdom courts for a male to be sterilised (2000), the study found that the parents view's on sterilisation did not vary as a result of their child's sex. The majority of parents felt that they alone or in conjunction with their GP should make the decision as to whether their child should be sterilised.

More recently, Brady (2001) undertook a review of applications for the sterilisation of people with learning disabilities to the Australia Family Court during the period 1992 to 1999. Brady considers a number of factors that may be relevant to the court's consideration; one such factor is the wishes of parents (Brady 2001).

The studies reviewed in this section are clearly limited, and the most recent UK study is almost a decade old. However, they do suggest that parents generally hold a negative view towards the expression of sexuality by their learning-disabled children.

1.4.7. The views of men and women with learning disabilities about their sexuality:

Very few studies appear to have been undertaken with the prime purpose of ascertaining what men and women with learning disabilities feel or believe about their sexuality[23]. There are, however, a few 'quality of life' studies such as those conducted by Alderson (2001), Davies and Jenkins (1997), and Sands and Kozleski (1994) that consider issues such as personal relationships. There are also a considerable number of studies concerned with the sexual knowledge of people with learning disabilities. Some of these also look at their attitudes to sexual behaviours. Finally, it is also possible to obtain some idea of the attitudes held by people with learning disabilities from some of the studies undertaken on carers' attitudes. This is because the carers were asked to report things such as whether the person they care for has expressed a desire to get married.

One such study that falls under the latter category is that of Pueschel and Scola (1988) (discussed in the previous section). They report that of the adolescents the study was concerned with, more than half had shown interest in the opposite sex, that 55% of them attended dances or other social gatherings and that 28% of the male adolescents and 43% of the female adolescents had expressed a desire to marry. However, few had expressed a desire to enter into a sexual relationship and only a quarter of them had boyfriends or girlfriends.

One of the first studies predominantly concerned with sexual knowledge in the period under consideration is that of Hall, Morris and Barker (1973). Their study was, unusually for the time, concerned with adolescents. Moreover, it was concerned to ascertain the difference between what parents thought their adolescent child's knowledge and attitudes to be and what the child actually knew and thought. The study, which took place in the USA, was of sixty-one non-institutionalised adolescents and their parents. It was found that the main disparity between how parents thought their child would respond and how their child actually did respond related to the childrens' attitude. Children displayed a more

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[23] Such studies will be discussed later in this section.

liberal sexual attitude than their parents thought they would. This being so, however, parents were generally sensitive to the self-perception of their children and to their sexual knowledge. Unfortunately the authors do not provide the reader with an outline of the subjects upon which peoples attitudes were being sought.

Hall and Morris undertook a further study, which they reported in 1976. This study compared the knowledge and attitudes of sixty-one institutionalised adolescents with those of sixty-one adolescents residing in the community. They found no difference between the groups in relation to self-concept or attitudes, but did find a difference in relation to sexual knowledge, with adolescents living in the community having a greater knowledge of socio-sexual topics (1976). As with their earlier study the reader is not informed as to the attitudes assessed.

A later study of adolescents' sexual knowledge and attitudes was carried out by Ousley and Mesibov (1991). Like Lunsky and Konstantareas later in the decade, they compared the knowledge and attitudes of a group of learning disabled individuals with a group of individuals with autism. As they had hypothesised, males from both groups showed the most interest in dating and sexuality. Likewise, their second hypothesis, namely that individuals with autism would have had less experience than individuals with a learning disability was proved. Their third hypothesis, namely that knowledge would be more dependent on experience than IQ was not confirmed. Rather, they found that IQ was a good predictor of sexual knowledge in both groups. Like many of the other studies under consideration, however, attitudes around sexuality appear to be assessed solely in relation to sexual behaviours. However, this being said, the results, namely that 37% showed interest in sexual activity whilst only 28% had experienced any sexual activity suggests that numerous people with autism and other learning disabilities were not receiving opportunities to express themselves sexually despite having a desire to do so.

Another study of sexual knowledge and attitudes was undertaken by Edmonson and Wish (1975). Their study was of eighteen American adult males with learning disabilities. In relation to the attitudes of men with learning disabilities they found that of the sixteen men who answered a question about whether masturbation was wrong, six said it was wrong, one said he did not know, and nine said it wasn't wrong. Those seeing it as wrong gave a variety of reasons for their beliefs which were mainly the result of prohibitions or false information. When the same men were shown a picture of a heterosexual couple engaging in sexual intercourse and were asked about their attitudes to such behaviour, four men said it was wrong, some because the actors had no clothes on and one because he believed you could be sent to prison. In relation to homosexual acts, six out of seven men recognising the fact that they were being shown two men embracing said it was wrong. Edmonson and Wish's assessment tool was developed into a widely used socio-sexual knowledge and attitudes test (SSKAT).

A later study by Edmonson, et al (1979) also involved some assessment of attitudes. In this study, they had a larger sample, which was comprised of forty-nine institutionalised males, fifty institutionalised females, fifty males and fifty females living in community settings in Ohio. They tested the sample's attitudes towards nine topics, seven of which related to sexuality, namely; dating, marriage, intimacy, intercourse, pregnancy, masturbation, and homosexuality. They found that community based women were the most conservative in many of their views whilst community based males were the most liberal in many of their views, though even they held fairly negative views about the topics in question. In relation to attitudes to marriage, institutionalised residents held more positive views and wished to get married than held negative views, whilst community based residents were more negative than positive about marriage. Edgerton, who reported a similar finding suggests that this phenomena is due to institutionalised individuals seeing marriage as being an important status because it shows them to be 'free and full members of the outside world' (Edgerton 1993, p.139), a view shared by McCabe (1993).

Another study interested in sexual knowledge, attitudes and behaviours is that undertaken by Timmers et al (1981). Their study in Wisconsin was concerned with twenty-five adults who had been placed in an 'apartment living programme', (seemingly similar to what in the UK would be referred to as 'warden controlled accommodation'). They found that the interviewees had mixed attitudes towards sexual activities. All the interviewees thought it was acceptable for a male to ask a female for a date and a large proportion thought it acceptable for a female to ask a male for a date. Additionally, all thought it was acceptable to kiss, hold hands, hug, and touch a date when clothed. However, when asked about touching when undressed only sixteen of the interviewees approved, though eighteen approved of sexual intercourse. Same sex behaviours, however, were generally disapproved of. At the time of the interview ten of the twenty-five interviewees were 'going steady' and twenty-one of the participants expressed a desire to marry, though some reported feeling pressured by their parents not to do so. The authors concluded that whilst people with learning disabilities could be viewed as part of the 'sexually oppressed' they did not feel that the subject group saw themselves in that light. In fact the authors felt that 'normalisation' was working with the participants who held attitudes to sexuality that reflected those of the general population (1981, p.37).

McCabe and Cummins, the authors of *SexKen-ID*, another socio-sexual knowledge and attitudes assessment tool designed for use with people with learning disabilities (McCabe and Schreck 1992), undertook a study in Australia. This sought to measure the knowledge, experience and feelings of thirty people with mild learning disabilities (McCabe 1993). They compared those results with the results from a group of fifty psychology students. They found that whilst people with learning disabilities had similar levels of knowledge to the psychology students in relation to menstruation and body parts they had less knowledge about dating, intimacy, sexual interaction, contraception, abortion, sexually transmitted infections, masturbation and sexual abuse. In relation to experience, more people with learning disabilities had experienced pregnancy or a sexually transmitted infection than the students. Additionally more of them reported masturbating regularly (cf. Bancroft 1989). However, people with learning disabilities had less experience of kissing, oral sex, 'feelings of intimacy' and sexual intercourse. There was little difference between the two groups in relation to contraception, homosexual experiences, dating current sexual partners and unwanted sexual contact. In relation to expressed feelings and needs, the students were generally more positive about the levels of privacy they enjoyed, about getting married and having children, masturbation, homosexuality and a wide range of sexual interactions. Overall, people with learning disabilities expressed more negative feelings towards most aspects of sexuality than the students. Whilst McCabe and Cummins suggest that the negative views expressed by people with learning disabilities may in part be due to a lack of sexual knowledge, they also posit the view that such attitudes may be the result of negative attitudes expressed by parents or caregivers.

A study by Konstantareas and Lunsky in Canada (1997) sought to compare the difference between the socio-sexual knowledge, experience and attitudes of individuals who were autistic with individuals with a non-specific learning disability. They interviewed a total of thirty-one individuals (seventeen males and fourteen females). They found very little difference in the sexual attitudes of either group. Generally, they endorsed few sexual activities, particularly homosexuality and masturbation. However, most participants showed interest in getting married and parenting, with many expressing their frustration at being unable to parent. Such a view is also expressed by Slattery, who when writing about her marriage discusses the sadness she feels about not having children (Slattery and Johnson 2000).

Lunsky and Konstantareas went on to compare the attitudes of the learning-disabled and autistic adults with the attitudes of two further groups, the first being comprised of twenty-five Canadian undergraduates and the second of twenty-eight adults from an American University who were roughly matched for age and gender with the learning-disabled and autistic adults (Lunsky and Konstantareas 1998). Interestingly, they found that the attitudes of men and women did not differ significantly in any of the groups and so aggregated the results. Participants were presented with a list of twenty behaviours / activities relating to sexuality. They found that individuals with learning disabilities expressed more conservative attitudes than any of the other groups and were particularly disapproving of situations around 'dating behaviour', masturbation and homosexuality. There was no significant difference between the two University samples. The authors were unclear as to why the individuals with autism were less conservative than the individuals with a learning disability, but posit the view that it may be a result of people with autism being less in tune to the reactions of others (such as carers) and thus less likely to take on their view.

Heyman and Huckle's study (1995) is one of the few that actually seeks to elicit the attitudes of people with learning disabilities directly. Additionally, it is one of the few British studies. As has already been stated (in section 1.5.6.) the study was of twenty adults with learning disabilities and their parents. The study was qualitative and involved the researchers interviewing adults with learning disabilities over a time-scale of 6-9 hours. These interviews were semi-structured and covered a wide range of issues relating to relationships. Of the twenty adults interviewed, only four expressed an unqualified wish for a sexual relationship whilst another four of them expressed a qualified wish for a sexual relationship. Most of the adults regarded sexual acts and sexual areas of the body as wrong or 'rude'. Despite this, many of them said that they had a boy or girlfriend and felt that a limited degree of intimacy, such as kissing and cuddling, was permissible. However, many of them had little privacy in which to partake of such activities and were heavily supervised which they resented. The main fears that the adults expressed in relation to sexual relationships were getting into trouble with 'authority' figures. No adults mentioned pregnancy as a concern and only four mentioned HIV / AIDS as a concern. Three of the twenty adults had experienced sexual intercourse, but these experiences were 'mechanical' and lacked intimacy. The adults who stated that they might like to develop a sexual relationship were inhibited predominantly by a lack of privacy and carer approval. Eight of the adults wanted to receive socio-sexual education contrary to the wishes of their parents. Like Shepperdson (1995), Davies and Jenkins (1997) and Jordan and Dunlap (2001), Heyman and Huckle point to the fact that adults with learning disabilities were not being permitted to make the transition to adulthood.

Another British study is that undertaken by McCarthy (1998). She undertook a study of seventeen women with learning disabilities over a period of three years. She was concerned to ascertain the women's perceptions of their body image, whether they were influenced to conform to social pressures and what level of control they had over their bodies. Of the seventeen women interviewed, she found that five liked nothing about their bodies and three simply regarded them as being 'all right'. Only three of the seventeen women were mostly positive about their bodies. When asked whether their bodies were a source of pleasure for them, either physically or psychologically, six of the women said they received no good feelings from their bodies, three did not know or did not reply, five mentioned one or two things about their bodies that gave them pleasure, and four said their sexual or private body parts gave them pleasure. Only two women said that everything about their bodies felt good. The women interviewed by McCarthy found it easier to say what it was about their bodies they disliked. Things they disliked included their perceptions of being too fat or too tall and two of the women stated that they disliked their genital area. Although four women said there was nothing that they disliked about their bodies three of them later said that there were things they would like to change about their bodies. When asked what they wished to change about their bodies, there was a wide-ranging response from 'everything' to 'having longer hair'. The change most frequently voiced was to loose weight. McCarthy notes that a number of the women referred to the way in which staff sought to influence or control their decisions about weight. She also posits the view that the women she interviewed had internalised society's expectations as to how slim they should be. She also found that some clients used personal hygiene as a means of taking control, that is to say that by not washing a woman was able to control part of her life and at the same time had a weapon with which she could annoy staff. McCarthy found that the level of control the women she interviewed had over their bodies varied. For example, some staff made personal comments about their appearance, other women had their personal space invaded by staff, and yet others had their choice of clothing ignored or overridden by staff who selected clothing for them. McCarthy also discussed contraception with women. Of the seventeen women, thirteen were using some form of contraception and a further two had used contraception previously. Although none of the women using contraception had been sterilised, a high proportion were using depot medroxyprogeterone acetate (Depo Provera). The high use of Depo Provera amongst women with learning disabilities is not limited to McCarthy's sample, and continues today as is seen from the research of Servais et al. (see also Van Dyke, McBrien et al. 1995; 2002). Of the fifteen women who were using or had used contraception, only one had made the choice herself. In all the other cases doctors, parents or staff had made the decision. Overall, the impression painted by McCarthy's research is that women with learning disabilities have poor self-images and little control over their bodies. More recent writing by McCarthy paints a similarly gloomy picture in so far as she states that the majority of women with learning disabilities with whom she has worked had lives that were *'largely devoid of sexual pleasure'* (2000).

A further British study of women with learning disabilities is that of Scior (2000). She undertook a series of in-depth interviews with five women with mild to moderate learning disabilities. Although the subjects covered in the interviews was quite wide, the main focus of the interviews was on the women's attitudes to gender and gender stereotyping. Scior found that the interviewees viewed women and men as being fundamentally different. For many the perceived differences were laden with value judgements and gendered stereotypes. Additionally, she found that most of the women subscribed to the romantic notion of heterosexual love and marriage. However, she also found that most of the women interviewed did not appear to be aware that they were entitled to be treated with the same amount of respect that non-disabled women would expect. She concludes by positing the view that normalisation has failed to tackle the devaluation of some groups on the basis of such things as gender or race.

Alderson (2001) undertook research into quality of life issues and pre-natal screening in London. As part of the study, she interviewed five individuals with Down's syndrome. One of the interview topics was 'enjoyments and hopes'. Of the five, three spoke about intimate relationships and parenting. All three said they would like an intimate relationship and would like children. However, as in Heyman and Huckle's study (1995), some of the interviewees saw relationships and parenting as concerned with risks, and others noted the lack of opportunity afforded people with Down's syndrome to enter into personal relationships.

Another study concerned with the way in which people with learning disabilities perceive their relationships and sexuality was undertaken by Lesseliers (1999) in Belgium. She interviewed forty-six adults with learning disabilities about a variety of topics relating to personal relationships and sexuality. Her main finding was that most of the people she interviewed did not distinguish between the feeling of being in love and its expressed behaviour. Most people expressed being in love in terms of doing things with a person, being nice to that person or taking care of them. This appears to be similar to the finding of Mattinson that companionship was one of the most important aspects of relationships amongst the couples she interviewed (1970). Like Heyman and Huckle (1995), Lesselier notes that for most people intimate activity was restricted to kissing, cuddling and hugging. Six of the participants in Lesselier's study did express a desire to go to bed with their boyfriend or girlfriend, but were never able to do so due to the fact that they were not afforded sufficient privacy. Those interviewees who did have a sexual relationship did so within stable and loving relationships in which they showed respect for one another and mutually consented to their experiences and experimentation.

1.4.8. Summary and Discussion

The first point of note in considering attitudes towards the sexuality of people with learning disabilities is the paucity of studies that seek to ascertain the general population's attitudes, parents' attitudes and, most importantly, the attitudes of men and women with learning disabilities. In fact, the statement by Ann and Michael Craft that,

" *The one thing that can be said with any certainty is that we really know very little about the attitudes of the mentally handicapped towards sexuality in general and their own sexuality in particular.*" (Craft and Craft 1981)

still holds truth today, over two decades later.

As previously alluded to, research into the attitudes of the general public towards the sexuality of people with learning disabilities is virtually non-existent. As a result of this it is not possible to draw any conclusions as to public attitudes.

In relation to employed carers' attitudes towards the expression of sexuality by people with learning disabilities although there are not large numbers of studies, there are sufficient to make some comparisons. Although the studies often show mixed results, they show that over the last three decades carers' attitudes have become increasingly positive or liberal. However, one must treat some of the studies with some caution due to the fact that they are generally concerned with the attitudes of staff attending sexuality workshops. The very fact that staff have, in most instances, volunteered to attend such workshops may mean that those staff held particularly liberal attitudes and had a personal interest in sexuality issues (Toomey 1993). See also Hogg et al (2001) and Hingsburger (1993).

In relation to parents' attitudes, it appears that their attitude towards the expression of sexuality by people with learning disabilities is essentially negative and has not visibly become more liberal over time. For many parents, the expression of sexuality by their learning disabled child is seen as problematic. Parents express similar concerns in the most recent studies to those expressed in studies undertaken in the 1970s. Such concerns relate to abuse, pregnancy, parenting and homosexuality.

Although men and women with learning disabilities have rarely been canvassed specifically for *their* opinions about their sexuality, the literature that is available suggests a number of things. The first thing to be noted is that men and women with learning disabilities are sexual beings and see themselves in that light. This is evident, not least, from the considerable amount of literature that reports people with learning disabilities expressing the desire to have long term sexual partners or to get married, e.g. (Lawrence and Swain 1993; Hepper 1999; Knox and Hickson 2001). In general, however, men and women with learning disabilities appear to hold more conservative attitudes to sexuality than people without learning disabilities. Additionally, the studies show a number of negative facts. These include the fact that women with learning disabilities have negative perceptions of their body image and their sexuality; that many people with learning disabilities have had negative sexual experiences; they lack privacy and the opportunities to develop relationships; they are heavily supervised; and carers seek to dissuade them from intimate relationships. Such factors support Timmers et al's conclusion that people with learning disabilities are 'sexually oppressed' (1981).

It is clear that sexuality, both generally and in relation to people with learning disabilities, appears a more acceptable discussion topic today than it was thirty years ago. That is not to say, however, that attitudes towards sexuality are generally liberal. In fact it has been argued that as a result of HIV and AIDS, attitudes towards sexuality are more conservative now than they were two decades ago (Grigg 2002). Leaving aside the so-called return to 'family values' to consider the sexuality of people with learning disabilities, there appear to be few writers on the subject, although some such as Hilary Brown, Paul Cambridge, Ann Craft, Michelle McCarthy and David Thompson have produced prolifically. Additionally at a practice level it would appear to remain the case that the sexuality of people with learning disabilities is a subject that most people would prefer to ignore. This is evident in a number of ways.

Firstly, it is evident if one looks at the training of learning disability nurses in so far as they generally receive very little education about sexuality issues or the time to consider them (Lewis and Bor 1994; RCN 2000; Wheeler 2001; White 2002). This is despite the fact that Learning disability nursing is the only 'professional' training specifically designed for people wishing to work with persons with a learning disability[24]. Other professionals such as social workers generally undertake a generic training that includes some relevant theory and placements. Likewise, teachers can no longer train solely to work in 'special education'.

Additionally a number of the 'leading' texts on learning disability fail to mention the subject. For example Hallas' *The care of people with intellectual disabilities* (Fraser, Sines et al. 1998), despite being written by authors eminent in the field of learning disability and containing sections on community inclusion, contains no mention of sexuality or personal relationships. Similarly, Flynn and Lemay's review of 25 years of normalisation makes no reference to the sexuality of people with learning disabilities (1999).

Even where the subject is referred to in texts, the emphasis is often on negative or 'problematic' aspects of sexuality such as abuse or sexually challenging behaviour (Behi and Edwards-Behi 1987; Jenkins 1989). For example, *Standards and Learning Disability*, a key text for student nurses contains a whole chapter on sexual abuse, but only a few sentences on positive aspects of sexuality (Thompson and Mathias 1998). Likewise, Barroff and Olley (1999)are essentially negative in their discussion of sexuality. For example, they stress the risks that face children of parents with learning disabilities, and in a chapter on 'maladaptive or challenging behaviour' discuss such things as unintended pregnancy, sexually transmitted infections and vulnerability to sexual abuse.

Even national guidance documents either ignore the sexuality of people with learning disabilities (RCN 2001; Department of Health 2001a) or merely pay lip service to the issue (National Assembly for Wales 2000a; Department of Health 2001).

In conclusion, one can see that the studies and literature discussed above demonstrate that the views of parents, staff and individuals with learning disabilities around issues concerning sexuality may be very different and may

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[24] However, as a result of recent policy changes, all direct care staff will have to undertake training specific to working with people with a learning disability through the LDAF scheme. One of the leading texts for this training Carnaby, S., Ed. (2002). Learning disability today. Brighton, Pavillion.

does contain a chapter that considers sexuality in a more positive light.

result in conflict between some or all of the parties involved (O'Hara, Carmichael et al. 1997; Hepper 1999; McDermott, Martin et al. 1999).

It is evident, therefore, that despite a growth in the number of specialist sex education materials available for women and men with learning disabilities, the widespread acceptance of normalisation and a move towards a rights based discourse, people with learning disabilities continue to be regarded as 'less than normal'. As a result of this the expression of their sexuality continued to be denied throughout the 1970s and 1980s (Heyman and Huckle 1995) and is rarely encouraged even today.

Rather than men and women with learning disabilities being encouraged to express their sexuality to their fullest potential, emphasis continues to be placed on the more negative aspects of sexuality such as abuse and sexually transmitted infections (STIs). Although it is important to protect people from abuse and infection, placing a strong emphasis on the prevention of abuse and the transmission of STIs including HIV has resulted in people being given socio-sexual education for negative reasons (Kempton and Kahn 1991). Moreover it has often resulted in them being overprotected and denied the opportunity to enter into relationships (Brown and Turk 1992; Brown 1994; Ames and Samowitz 1995; Koller 2000).

1.5. Possible reasons why people with learning disabilities are denied the opportunity to express their sexuality

1.5.1. Introduction

As was discussed in the previous section a considerable amount of literature has been published during the last two decades on the subject of men and women with learning disabilities and sexuality both generally, and more specifically on such issues as abuse and HIV. Additionally, numerous socio-sexual education packages and materials have been produced specifically for use with women and men with learning disabilities (e.g. Dixon 1988; Adcock and Stanley 1996; Scott and Kerr-Edwards 1999). As a result of this, and the virtually wholesale uptake of principles such as normalisation and John O'Briens 'five accomplishments' (1989) some progress has been made in preventing the abuse of people with learning disabilities. However, little progress appears to have been made in the way of supporting people with learning disabilities in the expression of their sexuality (Brown 1994; Edmonds and Collins 1999; Wolfe and Blanchett 2000). This section reviews the literature for possible reasons for this phenomenon.

1.5.2. A review of suggested reasons as to why the expression of sexuality by people with learning disabilities is not supported.

1.5.2.a. Normalisation:

One suggestion that has been posited as a cause of this phenomenon is the very philosophy of normalisation itself (Davidson-Paine and Corbett 1995). Although, as discussed in section 1.4.5., Nirje's original concept of normalisation may be regarded as supporting facilitation of the expression of (hetero)sexuality by people with learning disabilities, this egalitarian, rights-based concept of normalisation was replaced by the American version of the concept (Emerson 1992). This version of the concept, as propounded and reformulated by Wolfensberger had a different emphasis (Perrin and Nirje 1989; Chappell 1992).

Rather than being rights based, normalisation or 'social role valorisation' as reformulated by Wolfensberger is concerned with using culturally valued means to enable people to establish and / or maintain roles that are cultural ideals or socially valued (Brown and Smith 1989; Thompson, Bryson et al. 2001). In British society, however, many relationships and expressions of sexuality, although not illegal, are dis-valued, examples being transvestism, unmarried or teenage parenting and same-sex relationships.

Normalisation does not challenge society's views and celebrate difference (Dalley 1992). Rather, it accepts that heterosexuality is the norm with the result that non-heterosexual expression of sexuality is either not discussed or, is morally stigmatised (Brown 1994). In fact, normalisation encourages people to change themselves in order to be accepted in society (Walmsley 1991a; Corbett 1994; cf. Wolfensberger 1995; Williams and Nind 1999). Because of this it is seen by some as permitting only valued sexual expression, in short heterosexual sex within marriage (Rubin 1999; Sheerin and Sines 1999).

Despite the fact that being married and having children may be seen as a cultural 'ideal' in the United Kingdom, it may be argued that normalisation does not even result in the facilitation of heterosexual relationships. This is due to the fact that the principle suggests that relationships between people with learning disabilities are of less value than relationships between people with learning disabilities and non-learning-disabled people (Chappell 1992; Hingsburger, Snell Van Noort et al. 2000). It may be the case that people with learning disabilities might express a desire for sexual relationships with non-learning-disabled people. However, it is uncommon for non-disabled individuals to seek a consensual sexual relationship with a person with a learning disability other than where the non-disabled person is older and / or otherwise devalued themselves (Sinason 1992; Edgerton 1993).

As well as arguably being heteronormative and heterosexist, normalisation is also perceived as being sexist (Williams and Nind 1999). Because of this, issues such as gender, sexual abuse, unplanned pregnancy, and lack of enjoyment in sexual experiences have not been addressed other than by very few writers such as Brown (1996) and McCarthy (2000).

Even if normalisation is not regarded as a primary factor in the prevention of the expression of sexuality by people with learning disabilities, it may be seen to play a role in the continuation of such prohibition. This is due to the fact that the principle does not challenge socially held perceptions of people with learning disabilities. Nor does it seek to address power differences between people with learning disabilities and those without (Brown and Smith 1992).

1.5.2.b. Myths and beliefs:

Another factor that is posited as contributing to the fact that people with learning disabilities are not supported in the expression of their sexuality is the continued belief in a number of myths, two of which are contradictory. The first is that both men and women, but particularly men are sexual predators. This is referred to in a number of the studies considered in the last section, e.g. (Dawson 1993; Heyman and Huckle 1995; Block 2000) and in articles on the subject of sexuality and people with learning disabilities (Kempton and Kahn 1991; Bell 2001).

In opposition to this belief is the belief that people with learning disabilities are perpetual children who are asexual and in need of protection (Lundstrom-Roche 1982; Monat-Haller 1992; Burns 2000). This view is not restricted to parents, as Hingsburger et al. (2000) demonstrate when they cite the experience of a mother who was told by her doctor that "*her child's sexual organ was just a 'flap of flesh' that had no meaning for her child*" (Hingsburger, Snell Van Noort et al. 2000 p.8). It is unclear why this belief came into being. It may be the result of young adults with learning disabilities staying at home longer than their siblings or as a result of them requiring personal and intimate care into adulthood (Malhotra and Mellan 1996; Shakespeare, Gillespie-Sells. et al. 1996). It may also have been perpetuated by clinicians' references to people's mental age (Abramson, Parker et al. 1988) and the use of images of children to promote organisations such as MENCAP and The Spastic Society (now Scope). However the belief came about, it results in many people with learning disabilities being denied the opportunity to make the transition from childhood to adulthood (Davies and Jenkins 1997; Jordan and Dunlap 2001).

Other widely held myths relate to such things as people with learning disabilities being regarded as close to God and thus 'holy innocents' (Taylor and Bogdan 1989; Sheerin and Sines 1999), being seen as subhuman (Clements, Clare et al. 1995; Deeley 2002) or simply being considered to be asexual (Thompson, Bryson et al. 2001). Other myths are culture specific like the Bangladeshi belief that people with learning disabilities are possessed by a 'bhut' (ghost) (Hepper 1999).

A possible explanation as to why viewing people as 'subhuman' or 'eternal children' may result in hostility towards the idea of people with learning disabilities expressing their sexuality is provided by Caplan (1987). In considering the difference between sex, gender and sexuality, she notes that some people conflate gender and sexuality, arguing that gender is expressed through sexuality and that each sex has a specific sexuality. Caplan disputes this due to the fact that such a view denies a person a sexuality other than heterosexuality. Rather, she posits the view that a person may biologically be a man (sex) and have been socialised into being a man (gender or sex role) but may express his sexuality by loving another man. The fact that he loves another man changes neither his sex nor gender. She then goes on to state that such an anomaly or disparity between sex, gender and sexuality may be one of the reasons for society's suspicion of, and hostility towards gays and lesbians. It is arguable that this 'theory' is applicable to the situation that people with learning disabilities find themselves in. That is to say whilst they can be seen to be male or female (sex) they are regarded as being asexual or eternal children and thus neuter (gender). For them to express their sexuality in any way is thus an anomaly.

1.5.2.c. Service provision:

A further explanation for the fact that people with learning disabilities are not being supported in the expression of their sexuality may lie in the way that services are provided and managed. Firstly, it is arguable, as a result of competitive tendering, that people with learning disabilities are regarded as little more than commodities (Brown and Smith 1992; Cambridge 1997a). One sees service providers, including private and not for profit making organisations, seeking to ensure that their bid to provide services is as inexpensive as possible in order to be awarded the service contract (Cambridge 1996; Cambridge 1997a). At the same time, those learning disability hospitals that currently remain open have been given closure dates and are thus seeking to disgorge their residents into the community. As a result of these two factors, people with learning disabilities are frequently placed in what are in reality 'abnormal' environments. For example, it is commonplace for two or three disparately matched men to be placed in a house together (Sheerin and Sines 1999) even though such a set up is unusual outside of learning disability and mental health services. Learning-disabled individuals generally have little choice as to where they are moved, as services predominantly seek to resettle individuals to the area they originated from. Nor, generally, do people with learning disabilities have real choice as to who they are to live with (Brown and Smith 1992; Cambridge 1997a). Accommodation is often small and provides little in the way of privacy or space where those residing there could entertain friends or companions without interruption (Heshusius 1982; Sundrum and Stavis 1994; Collins and Cozens 1999). Moreover, people are frequently under constant surveillance both inside and outside their accommodation (Giami 1987).

Additionally, staff supporting people living in such environments are often young and inexperienced in the care of people with learning disabilities. As a result of this they are unlikely to be appropriately trained in assisting people (McCabe

1993) to explore their sexuality and its expression (Fairburn, Rowley et al. 1995; Aylott 1999; Burton, Valenti et al. 2000). Additionally, they may find the discussion of such issues uncomfortable (Sharkey 1997) or be concerned that it may lead to difficulties for female staff in defining appropriate boundaries with male clients (Thompson, Clare et al. 1997) or vice versa. Even if staff are willing and appropriately trained to assist clients in the exploration and expression of their sexuality, there may be numerous barriers, both real and perceived, some of which are discussed below, that prevent clients developing their sexual identity (Ames and Samowitz 1995; Edmonds and Collins 1999). It remains the case that some services do not provide clear guidance or policies on sexuality. This may be another factor which discourages staff from supporting clients in this aspect of their lives (Aylott 1999; McConkey and Ryan 2001).

Once people have been placed in accommodation provided by a service, although they may not like the house they live in, the people they share the accommodation with, or the staff that support them, it is extremely difficult for them to secure an alternative placement unless they exhibit extremely challenging behaviours. Placing clients in these abnormal environments results in them having minimal, if any, opportunity to explore their sexuality and express it in a socially acceptable manner (Brown 1994; Aylott 1999).

Even where people do not live in service provided accommodation, but live with their family, they may be denied the opportunity to develop sexual relationships, take part in community activities or use facilities that non-learning-disabled individuals of similar age would use (Behi and Edwards-Behi 1987) due to their family's perception of sexuality as a hazard (Heyman and Huckle 1995).

1.5.2.d. Economics:

Another possible reason why the expression of sexuality by people with learning disabilities is not supported relates to economics. At the macro level, women and men with learning disabilities are generally viewed as a surplus population who do not contribute to the economy. Rather, society has to maintain this population who are seen as unproductive not only financially, but also in relation to such things as the family, the sciences, the arts, and politics (Farber 1968; Walmsley 1991a). Moreover, it has until recently, been presumed that if men and women with learning disabilities were to have children the children would have to be removed from them and reared at the expense of the state (Keywood 1995). Given such perceptions, it is not surprising that society at large should express negative views towards the expression of sexuality by women and men with learning disabilities. For as Brown (1994) argues, if people with learning disabilities assert their right to express their sexuality they are challenging the generally held idea that being able to express your sexuality is a reward for being economically self sufficient.

At the micro level, sexuality is shaped by numerous factors. One such factor is economics. This is due to the fact that economics has a bearing on such things as where a person lives, who they live with, what they wear, where they go, and what they do (Gilbert 1993). These factors and others relating to economics affect a person's ability to express their sexuality (Cambridge 1997a; Battacharyya 2002).

Most people choose friends or partners with attributes not hugely dissimilar to their own (Sinason 1992; Chappell 1994). Given that most people with learning disabilities do not work, they are only likely to meet potential friends and partners through leisure activities. Even if they do work, such work is often part time, poorly remunerated and may provide little contact with other employees (Riddell, Baron et al. 2001). However, people with learning disabilities are often dissuaded from attending groups and clubs such as 'Gateway' or 'Friendly Friday' where they would be with other people with learning disabilities (Brown and Smith 1992; Chappell 1994). Rather, friendships with people without learning disabilities are seen to be preferable (Knox and Hickson 2001). However, whilst this is the case, people with learning disabilities are generally ill able to afford a 'normal' social life. Given that attending and gaining entrance to places where one might meet a potential partner costs money, opportunities for finding a person with whom individuals may enter a relationship are diminished (Collins and Cozens 1999). Even if they do have sufficient funds to undertake social and leisure activities, there may well be numerous other factors that result in people having reduced opportunities to undertake such activities. Examples include a lack of transport, lack of choice, lack of social or other skills required to participate in activities or insufficient staff to support such activities (Sands and Kozleski 1994; Nunkoosing and John 1997; Walker and Walker 1998). A possible result of the above is that those clients who wish to have sexual experiences have no opportunity other than to participate in sexual behaviours and activities that may have little or no emotional component to them or may place them at greater risk of abuse and sexually transmitted infections.

1.5.2.e. Law:

A reason given by carers as to why they do not support people with learning disabilities in expressing their sexuality relates to law (Cambridge 1997a). In the past, staff may have held legitimate concerns that any action taken by them in relation to the facilitation of expression of sexuality by the men and women they care for may have fallen foul of the law. The concern arose due to the fact that people with learning disabilities were not only subject to the same laws relating to sexual acts as any other individual, they were also subject to additional laws. Such laws were contained in the Sexual Offences Acts of 1956 and 1967 as amended[25].

Until 1890, people with learning disabilities were subject to the same laws concerning sexual behaviour as non-learning-disabled individuals. However, as discussed earlier (in section 1.4.), during the late nineteenth and early twentieth-centuries men and women with learning disabilities became the central focus of the then current debate on 'degeneracy'. The legislation resulting from this concern, the 1913 Mental Deficiency Act, created five offences specifically concerned with sexual acts and people with learning disabilities.

The legislation was amended on a number of occasions between 1913 and 2003, and two new Mental Health Acts were introduced. The first of these two Acts, the 1959 Act, actually widened the scope of one of the sexual offences contained within the 1913 legislation. Section 127 of the 1959 Mental Health Act made it an offence for a man to have unlawful[26] sexual intercourse with *any* woman who was a defective regardless of her status under the mental health legislation. The Act maintained other sexual offences that had been contained in the 1913 Act. It also

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[25] At the time this study was undertaken, the law appertaining to the lawfulness of sexual activity was contained in the Sexual Offences Act 1956 as amended. On the 1st May 2004 the Sexual Offences Act 2003 came into force. Although the 2003 Act has considerable implications for people with a learning disability Wheeler, P. (2004a). "Sex, the person with a learning disability and the legal framework." Learning Disability Practice 7(3): 32-38.
the law discussed in this section and in interviews with participants in the study relates to the law in force prior to the 1st May 2004.

[26] 'Unlawful' simply meant 'out of wedlock' as at the time of the enactment of the Sexual Offences Act 1956, it was not legally possible for a husband to rape his wife. It is now a superfluous word.

re-enacted a provision originally contained in s.324 of the Lunacy Act of 1890, namely that it is an offence for a male employed in a hospital or mental nursing home to have unlawful sexual intercourse with a female or commit buggery or gross indecency with a male when that woman or man are patients.

In addition to maintaining offences contained within earlier legislation, the 1956 Sexual Offences Act introduced a new offence that provided that 'defective' males could not consent to touching that would, without consent, amount to indecent assault. In 1967, a further Sexual Offences Act received Royal assent. This decriminalised certain homosexual acts in certain situations. However, s.1 (3) of the Act specifically provided that a 'severely subnormal' male could not, in law, consent to a homosexual act. However, following amendments to the age of consent for homosexual acts in 1994 and 2000, it was no longer clear whether it was the case that, in law, a mentally impaired male could or could not consent to such acts (Wheeler 2003a). If Gunn (1996) was correct, then one was left with the somewhat bizarre situation that a male with learning disabilities could consent to a homosexual act if he had sufficient capacity, yet may not lawfully consent to touching that would, without his consent, amount to an indecent assault.

It may be argued that the law in relation to sexual acts and women and men with learning disabilities was necessary in order to protect them from abuse. However, such an assertion can not go unchallenged. Whilst evidence indicated that men and women with learning disabilities were more vulnerable to sexual abuse than other adults (Brown and Turk 1992; Blackburn 1995; Brown, Stein et al. 1995) the number of prosecutions brought under the pre 2003 legislation specifically aimed at protecting 'defectives' was extremely low. For example, whilst there were 37,792 reported prosecutions for sex offences in 1999/2000, during the period 1996 to 2000 there were only thirty-five prosecutions in England and Wales under ss.7, 9, and 27 of the Sexual offences Act 1956 and s.128 of the Mental Health Act 1959 (Home Office Crime and Criminal Justice Unit 2002; Wilkins 2002). The reasons for this are numerous, and include issues such as capacity to consent, the criminal justice system and rules of evidence. Such reasons are discussed elsewhere (Parker and Abramson 1995; Valenti-Hein and Dura 1996; Murphy and Clare 1997; Wheeler 2003a). However, these laws, and specifically s.27 of the 1956 Act (as amended by s.127(1)(b) of the Mental Health Act 1959), served to discourage formal carers from facilitating the expression of sexuality by people with learning disabilities. This section made it an offence for anyone who assisted in the control of any premises to induce or knowingly suffer a defective woman to resort to or be on the premises for the purpose of having unlawful sexual intercourse with a man or men.

Further legislation that may have served to discourage carers from such activity was contained in the Sexual Offences (Amendment) Act 2000. This Act lowered the age of consent to homosexual offences to sixteen. However, it also introduced new offences aimed at preventing 'abuse of trust' of sixteen and seventeen year old youths by people aged over eighteen who were in defined positions of trust in relation to the youths.

The law in force prior to May 1st 2004 law promoted the idea that people with learning disabilities were incapable of expressing their sexuality. Additionally, it failed to acknowledge that sexuality was not an innate biological drive but was shaped by numerous other factors. This can be seen in the 1999 case of R v Jenkins (unreported) where the judge, in summing up for the jury, stated that merely by, *"...submitting to her animal instincts...,"* the victim could be regarded as having given her consent (Winchester 2000b). These factors combined with the fact that the offences contained in the 1956 Sexual Offences Act left carers in an uncertain position if they wished to support clients in a sexual relationship arguably resulted in a lack of support for people with learning disabilities expressing their sexuality. For whilst few prosecutions under the 1956 Act occurred, the possibility of a two year term of imprisonment may have served as a disincentive to carers who considered facilitating the sexual expression of those men and women with learning disabilities for whom they cared as may the existence of common law offences of complicity. Likewise the 'abuse of position of trust' legislation may have served to prevent carers from, for example, giving information, advice or guidance to a sixteen or seventeen year old client about masturbation.

1.5.2.f. Self-Image:

Another reason why the expression of sexuality by people with learning disabilities may not be supported relates to body image and the 'belief' that only those who are young, attractive and physically healthy are entitled to express their sexuality.

Whilst this may be more of an issue for people with physical disabilities than learning disabilities, it appears to be of growing importance to all whether or not they have disabilities (Thompson, Bryson et al. 2001).

Concern about body image is not a new phenomenon, for example, the Chinese bound the feet of women, and western women have bound their breasts and worn corsets in order to present themselves as a certain shape (Ogden 1992). At one time, body image, although ostensibly for the benefit of men, was seen to be predominantly the concern of women. Despite there being the image of 'ideal men' portrayed in literature and on film, there was little pressure on men to conform to a certain shape.

However since the 1980s there has been growing pressure on men to look a certain way. For example, men are required to regulate their body fat in order to demonstrate that they have self-control and are successful (Stearns 1997). These pressures come from other men, from women and the media. However, although men may be more concerned with their body image, including such things as height, weight, hair loss, and penis size than they were twenty years ago, Ogden (1992) argues that men's body-image does not affect their self-image to the same extent as women's body-image affects their self-image. That is to say that although men may see themselves as being overweight, for example, they do not generally perceive their physical attractiveness (or otherwise) as being an essential part of their feelings of self worth or overall attractiveness (Ogden 1992).

Shakespeare, et al (1996) undertook research into sexuality and disability, interviewing forty-two disabled persons predominantly from Tyneside and London. One of the things they considered to be a barrier against being sexual was body image. They found that because people with disabilities are socialised within a society that emphasises beauty and normality, many people with disabilities internalised society's views. This fact was also noted by Thompson (1994) in relation to attitudes held by men with learning disabilities towards homosexual behaviour and by McCarthy in relation to attitudes held by women with learning disabilities towards bodyweight (McCarthy 1998). Because of this internalisation of societal views on body image, Shakespeare et al (1996) found that many of the people with disabilities who participated in their research held negative views about themselves and other people with disabilities. Although the majority of their work was with people with physical disabilities some of the interviewees had learning disabilities.

Most of the people they interviewed were able to provide the researchers with summaries of what society saw as 'acceptable appearance' and 'the body beautiful'. They also acknowledged that they felt at a disadvantage to non-disabled persons when seeking a sexual partner. This was particularly seen to be the case for women with disabilities, both straight and lesbian. However, gay men with disabilities also felt that they were judged predominantly by appearance. The authors quote a gay man with learning disabilities who noted the emphasis placed on beautiful bodies by the gay community and described his experience that if your disability was not 'acceptable', such as having an amputation or a HIV related disability no-one would be interested.

Some men with disabilities felt that they were not seen as masculine by non-disabled people and were treated more as women, for example, they were not expected to fight, and they were not expected to have control over money. This sexual oppression resulted in role conflict. They were expected on the one hand, as a person with a disability to be meek, mild and childlike, whilst on the other hand as a man, they felt they should be masterful, have leadership qualities and express anger (Shakespeare, Gillespie-Sells. et al. 1996), p. 62. As a result of this, some of the men with disabilities saw themselves as 'disabled men' rather than 'heterosexual men'.

1.5.2.g. Socio-sexual education:

Because people with disabilities do not generally comply with sexual stereotypes, they are often denied sexual status and seen as asexual. As a result of this they are often provided only with a limited socio-sexuality education or are denied one altogether. They can then only learn about sex and sexuality from peers and carers. Given that the sexual experience of many people with learning disabilities is negative (McCarthy 1993; Thompson 1994; Hepper 1999), informal peer education may result in the expression of sexuality being seen only in a negative light.

A further factor that may prevent people with learning disabilities being supported in the expression of their sexuality is the way in which much of the literature discussing sex, sexuality and sex education, particular since the mid nineteen eighties, has emphasised negative aspects of sexuality such as abuse, infection or unwanted pregnancies (Behi and Edwards-Behi 1987; Kempton and Kahn 1991). Likewise, many 'sexuality' policies emphasise protection from abuse and disease (Landman 1994; Shakespeare, Gillespie-Sells. et al. 1996). The emphasis on these issues has almost been to the exclusion of positive aspects of sexuality (Collins and Cozens 1999; McCarthy and Thompson 2000). Such an emphasis fails to allow a person with a learning disability the opportunity to make decisions about their sexual behaviour. Rather, it places the service provider in a paternalistic position in that they are then seen to be responsible for protecting the person with learning disabilities from such things. Additionally this emphasis further adds to the belief held by many that in relation to people with learning disabilities the expression of sexuality is a hazard to be managed if it can not be avoided (McCabe 1993; Heyman and Huckle 1995; Cambridge 1997a).

1.5.2.h. Power relations:

The penultimate factor to be considered as a possible cause of people with learning disabilities not expressing their sexuality is the issue of 'relations of power'. People with learning disabilities are generally disempowered, often by those responsible for their care (Brown and Smith 1992; Davies and Jenkins 1997; McConkey and Ryan 2001). Although most men and women with learning disabilities live in 'ordinary' housing in the community rather than in large institutions, many have little more say over their lives than those who previously resided in large institutions. For example, a person might be invited to attend his or her 'shared individual programme' or 'individual programme planning' meeting at which his or her life is planned for a period of time. However, few individuals will have the opportunity to contribute to such meetings because of such factors as their cognitive or communicative abilities (Carnaby 1997). Even if they fully comprehend what is being discussed and are able to make their wishes known, it is frequently the case that the 'professionals' present will be able to 'convince' the client that the options being offered, (those the professionals wish to be put in place,) are the best options (Stalker and Harris 1998; Wheeler 2001; Deeley 2002). Thus in reality the client has little say in such matters as who they live with, if and where they work, and how they spend their leisure time (Brown and Smith 1992). It can be seen, therefore, that people with learning disabilities have little power in many aspects of their life and are ill placed to assert their rights (Craft and Brown 1994; Cambridge 1997a).

Power relations are as important in relation to sexuality as any other aspect of a person's life as has been discussed earlier (section 1:2). For example, the fact that people with learning disabilities are generally disempowered results in them being more vulnerable to exploitation, abuse (Thompson 1994; Davidson-Paine and Corbett 1995) and sexually transmitted infections (Cambridge 1997a). Additionally, women and men with learning disabilities have little control over their body image, for example, staff may, amongst other things, control clients' dietary intake, obtain clothing for them or choose their hairstyle (McCarthy 1998).

1.5.2.i. New eugenics:

The final factor to be considered as a reason why people with learning disabilities are not supported in the expression of their sexuality is that which has been referred to by Kevles (1995) as 'the new eugenics', and by others such as Ward (2001), and Peterson and Bunton (2002) as the 'new genetics'.

As was discussed earlier (section 1.4) one of the main factors leading to the supervision, sterilisation, segregation and passing of laws relating to the sexuality of people with learning disabilities, was the influence of the eugenics movement. Although the movement lost its following and acceptability after the Second World War, a number of authors have suggested that public attitudes towards people with learning disabilities continue to be influenced by eugenic beliefs (Antonak, Mulick et al. 1995; Iredale 2000; Bailey, Barr et al. 2001). This can be seen from the fact that eugenic sterilisation of men and women with learning disabilities continued until 1972 in Canada (Nemeth and Johnson 1995; Holden 1998), until 1973 in the United States of America (Kevles 1995) and until very recently in Australia (Anonymous 1997; Carlson, Taylor et al. 2000; Brady 2001). Whilst eugenics has never been stated to be a reason for the sterilisation of women with learning disabilities within England and Wales, both Keywood (1995; 2001) and Knifton (1998) posit the view that judgments in UK sterilisation cases are influenced by eugenic ideology.

1.5.3 Summary:

We can see therefore, that there are numerous possible reasons why people with learning disabilities may not be supported in the expression of their sexuality. Reasons discussed include normalisation, myth, service provision, economics, law, society's idealisation of the human body, the emphasis placed on negative aspects of sexuality, power relations and eugenics. Whether and to what extent these reasons affect the ability of men with learning disabilities to express their sexuality is unclear, but it is hoped that that the research undertaken towards this PhD will go some way to answering such questions.

Part 2: Methodology

"*We do not have perfect theoretical and epistemological foundations; we do not have perfect methods for data collection; we do not have perfect or transparent modes of representation. We work in the knowledge of our limited resources. But we do not have to abandon the attempt to produce the disciplined accounts of the world that are coherent, methodical and sensible.*" (Atkinson 1992, p.110)

2.1 Introduction

This part of the dissertation outlines the theoretical perspective which informed the study and its methodology. It also seeks to provide justification for various choices, such as the choice of a qualitative methodology rather than quantitative, the choice of Interpretative Phenomenological Analysis (IPA), and the selection of participants. The aim of this section is to provide the reader with a better understanding of the study and the opportunity to replicate it should they so desire (Banister, Burman et al. 1994). It is also included in an attempt to demonstrate methodological rigour, thereby addressing the frequent criticism that qualitative studies lack this (Altheide and Johnson 1998; Maggs-Rapport 2001).

2.2. Theoretical Considerations:

2.2.1. Introduction

Whilst it is possible to approach a subject without basing it on a particular theory, it is customary, at least within a PhD, for the author to outline the theoretical perspective from which they are approaching the subject matter (Silverman 2000). By 'theoretical perspective' I am simply referring to an approach, which may be used to frame problems, solve problems and help one understand and / or explain social reality (Schwandt 2001). For example, the findings of a study may be assessed in relation to that perspective in order to ascertain whether they are in line with the theory and whether they contribute to that theory. Clearly, a person has a wide choice of 'theories' upon which to draw. In this section of the literature review I shall briefly outline Queer Theory and Disability Politics, both of which might be considered appropriate frameworks for approaching this work. The reasons for not selecting them are also discussed. I then outline 'social constructionism', this being the theoretical perspective I have chosen to loosely follow. I shall then briefly outline the reason for my choice of theory.

2.2.2. Queer Theory:

Prior to the late 1980s, the use of the term 'queer' when referring to homosexuals or bi-sexuals was considered highly pejorative and oppressive (Gamson 1995). However, during the late 1980s 'Queer Politics' and 'Queer Theory' emerged from Lesbian, Bisexual and Gay studies (Sandfort and Galesloot 2000). The emergence of Queer Politics in the late 1980s has been traced back to such things as a backlash against lesbian and gay gains, the AIDS 'crisis' and the eruption of internal differences relating to such things as gender and race amongst the gay and lesbian movement (Gamson 1995; Epstein 2002). Queer Theory may also be traced back to the late 1980s, to a number of predominantly North American academic conferences (Plummer 2000). It is suggested that the roots of Queer Theory can be traced back to such phenomena as constructionist history and sociology, feminist theory and post-structural philosophy (Krouwel and Duyvendak 2000; Weeks 2000).

Major aspects of Queer Theory are the emphasis of marginalisation, the problematisation of sexual and gender categories and identities and the rejection of civil rights strategies in favour of a politics of carnival, transgression and parody. Queer Theory and Politics are associated with organisations such as Outrage in the UK and Act Up and Queer Nation in the United States of America (Epstein 2002). Through the actions of such organisations, Queer Politics and Queer Theory are defiantly and, some might argue, provocatively asserted. Examples of such actions include 'kiss-ins', and 'outings'.

Although Queer Theory does have some appeal in that it recognises the experience of marginalisation and disputes absolute borders of such things as gender and identity, there were a number of reasons for not choosing it as the framework upon which to base this study.

Firstly, the confrontational defiance of Queer Politics and Queer Theory may alienate non-learning-disabled people who might otherwise be sympathetic towards the rights of women and men with a learning disability (Sandfort and

Galesloot 2000). Such 'in your face' approaches as are used by Queer Politics also conflicts with the approaches of civil rights strategists (Leck 1995). For civil rights strategists, rights are obtained by demonstrating similarity to the majority population in a manner that is not perceived as threatening by the majority population (Wilson 1995a) or by policy makers (Carabine 1995). Queer Theorists, on the other hand, emphasise difference and thus set themselves outside of mainstream politics. To adopt a Queer Politics / Queer Theory approach would only serve to highlight the difference between the majority population and those with learning disabilities. To do so would appear to be contrary to the work of organisations such as People First who have expended considerable energy emphasising the fact that they are 'people' and their similarities with the non-learning disabled population. Whilst a civil rights approach may not be a panacea to all the difficulties faced by women and men with learning disabilities, such an approach has been given increased legitimacy within the United Kingdom in recent years as a result of the enactment of the Human Rights Act 1998. To adopt an approach such as Queer Theory, which is so contrary to a civil rights approach, without having first fully explored the possibilities a civil rights approach may offer appears somewhat precipitous.

On a more positive note, Queer Theory does not accept binary definitions such as gay / straight; female/ male; disabled / able bodied; and black / white because they are seen to limit the exploration of sexual boundaries (Leck 1995). However, despite this, Queer Theory has been criticised for failing to tackle institutions such as medicine, law or established religion all of which create and enforce such binary definitions where one is favoured and the other viewed negatively (Caplan 1987; Gamson 1995). Given that such institutions have had considerable effect on the way in which men and women with learning disabilities are perceived and treated I believe it important to use a theoretical standpoint that has been used to tackle such institutions.

A final reason, for not choosing Queer Theory is that it is regarded as elitist and academic, operating predominantly through the use of highly abstract language (Stein and Plummer 1994; McLaren 1995). Given that it is aimed that this study should inform practice, policy and future research, it is my opinion that Queer Theory would make such aims less readily achievable.

2.2.3. Disability Politics

Prior to the early 1980s people with disabilities living in the United Kingdom had begun to challenge their marginalisation (Oliver 1990; Shakespeare, Gillespie-Sells. et al. 1996). However, since then, and in particular following the 1981 creation of the British Council of Organisations of Disabled People, people with disabilities have developed coalitions of disabled people and have campaigned in relation to numerous issues such as direct payments, anti-discriminatory legislation and accessible transport. In recent years, in addition to 'normal' political lobbying, a number of people with disabilities have used direct action in order to make their voices heard (Shakespeare, Gillespie-Sells. et al. 1996). Examples include chaining themselves to buses and police station steps in order to demonstrate the lack of accessibility to public services and buildings.

Although there is a diverse range of groups and organisations relating to disabled people one thing they generally have in common is the theoretical model upon which they are based. This model is known as the 'social model' (Oliver 1990; Oliver 1996). The main thrust of the argument of this model is that people with 'impairments' are disabled, not by their bodies, but by the society in which they reside. For example, the disabilities associated with a spinal injury are a failure of society to provide such things as appropriate access to buildings and public transport.

Sexuality is arguably one area in which people with 'impairments' are disabled by society. This may be the result of societal attitudes such as that people with disabilities are asexual, or because of an unwillingness on the part of service providers to facilitate sexual relationships (Shakespeare, Gillespie-Sells. et al. 1996). However, whilst people like Shakespeare (1996) have written widely on the subject of sexuality and disability and there are journals relating to this subject, such as 'Sexuality and Disability', published by Kluwer Publishing, sexuality is often seen as an unimportant aspect of a disabled person's being (Blackburn 2002), particularly where the disabled person is not a young, otherwise physically healthy male.

Although there are reasons why the use of Disability Politics may be considered an appropriate theoretical basis for this study, a number of reasons exist for not so doing. Some of these are similar to the arguments rehearsed in relation to Queer Theory, such as the danger of alienation resulting from using 'direct action' and the fact that rights based arguments are more appealing (Wendell 1996). Additionally, the following issues specific to Disability Politics were considered. Firstly, that the disability movement is predominantly concerned with physical disability and tends to ignore people with learning disabilities. For example, Oliver (Oliver 1990) who is generally considered one of the leading academics writing about disability and the 'social model' makes only seven minimal references to the 'mentally handicapped'. Likewise in his later book, 'Understanding Disability: From theory to practice' (Oliver 1996) he makes only one specific reference to women and men with learning disabilities, noting that their poverty and lack of access to such things as transport and housing are, like 'disabled people' the result of a lack of the success of either collectivist or individualistic approaches to welfare (Oliver 1996, p. 50).

Secondly, the sexual politics of disability in general and disabled masculinity in particular are generally ignored by those undertaking research into disability (Shakespeare, Gillespie-Sells. et al. 1996). Even where writers do consider the issue of disabled masculinity, this is generally in relation to that of physically disabled men and not men with learning disabilities. For example, Blackburn (2002) in her book on sexuality and people with spina bifida and hydrocephalus relates predominantly to the participants' physical difficulties and virtually ignores learning disabilities including only two paragraphs specifically concerned with this subject in the whole of her book. Likewise, although Shakespeare, et al (Shakespeare, Gillespie-Sells. et al. 1996) do interview some men with learning disabilities, they acknowledge that people with learning difficulties were not adequately represented in the research (Shakespeare, Gillespie-Sells. et al. 1996, p. 12).

2.2.4. Social Constructionism – A brief outline:

When introducing a subject or theory, it is customary to offer a succinct definition prior to discussing it in greater depth. However, social constructionism does not lend itself to such definitions for two reasons. Firstly, to provide a simple definition is regarded as being anti-constructionist in that it would suggest that constructionism may be objectively defined. Given that constructionism rejects realist accounts of phenomena, a definition would be an anathema to those following a social constructionist perspective (Potter 1996). Secondly, social constructionism is a broad concept that encompasses numerous approaches and has been developed in a variety of disciplines (Burr 2003; Gergen and Gergen 2003). Rather than provide a definition, I shall list some of the approaches that have been referred to as being constructionist and consider what common characteristics they may have.

Some versions of social constructionism are stronger than others. The weaker version does not posit the view that every object, concept, or aspect of the world is socially constructed. That is to say, it does not deny 'reality' in its everyday usage, but focuses on how our experiences or classifications of something are socially created. The stronger version of social constructionism, however, appears to deny or reject the assumption that there is an 'independent reality' (Goode and Ben-Yehuda 1994; Schwandt 2001; Barker, Pistrang et al. 2002).

As well as 'strong' and 'weak' forms of social constructionism, Burr (2003), amongst others, posits the view that social constructionism may be categorised as being either micro or macro in nature. She suggests that micro social constructionists view social construction as taking place in the interactions or discourse of people and are thus more concerned with the interactions of individual social actors. As a result of this, individuals are seen to have personal agency. Macro social constructionists, on the other hand, are said to be more concerned with the concept of power in relation to such things as social structures and institutions. They tend to analyze and challenge social inequality through research and practice. Unlike micro social constructionism, macro social constructionists tend to see the individual social actor as having little personal agency and as a result of this little ability to initiate change. However, having categorised social constructionists as either micro or macro, Burr does acknowledge that they need not be mutually exclusive, recognising that the two approaches may be synthesised (Burr 2003:22).

Approaches that have been said to fall under the umbrella of social constructionism include conversation and discourse analysis, ethno-methodology, feminist studies, post-modernity and post-structuralism, post modern political science, the sociology of knowledge, critical legal theory, critical psychology and symbolic interactionism (Potter 1996; Burr 2003).

Having stated that one can not, and should not, seek to succinctly define social constructionism, it is possible to outline a number of characteristics generally common to the approaches listed above. Firstly, the approaches have tended to be developed at the margins or intersections of a number of disciplines such as philosophy, sociology, politics, and social psychology. They are a collection of post-modern approaches attempting to understand how social actors within society construct their reality and how they come to share that reality with others. The approaches tend to be critical in their viewpoint and oppose the realist assumptions of traditional scientific positions, particularly the positivist view that the nature of reality is that which is observable and measurable. Rather, than talking of one reality, they are likely to consider that there are numerous realities and that social actors construct their own reality (Ekdawi, Gibbons et al. 2000; Gergen and Gergen 2003). This allows for different views to be considered without privileging one view over another. As a result of this, social constructionists tend to be interested in how and why a particular world view is imposed on people's experience (Barker, Pistrang et al. 2002). For example, they may consider why a person comes to be labelled as 'mentally ill' rather than a 'prophet' or 'bad'.

They generally stress the cultural and time specific nature of concepts and categories that we use (Burr 2003; Gergen 2003). For example, whilst homosexual love was an accepted form of sexual expression in Ancient Greek society (Foucault 1984), in the United Kingdom and other parts of Europe it was, until recently, seen as an unnatural practice and criminalized. Moreover, it was regarded as a form of mental disorder in the United Kingdom and America until the early 1970s (Bancroft 1989). Not only are the concepts considered to be historically, culturally and relationally specific, but they are also seen to be products of the particular culture and time in question, arising from relationships and such things as the social and economic factors present in that culture at that particular time.

They also consider language or interaction to be central to the construction of reality. Language is not seen simply as a way of describing or representing our world, but as a constructive or performative force (Mehan 1996; Burr 2003). For example, when a priest states, 'I baptize you,' or a magistrate states, 'I am adjourning this hearing until social and psychiatric reports have been completed,' they are not simply describing something. Rather, their language has consequences (Searle 1995). Likewise, language may bring about social change. For example, Oliver's (1990) use of the term 'disabled people' emphasised the fact that disability is a social restriction or construct, which required change, not on the part of the individual, but on the part of society. Since Oliver published his work, the 'social model' of disability has been widely adopted and calls for legislative changes have resulted in the enactment of the anti-discriminatory legislation. Moreover, knowledge and reality are not seen as existing other than through the interactions of social actors (Barker, Pistrang et al. 2002). Although it is not clear what the precise relationship is, social processes, social structure and interaction are seen to both shape, and be shaped by people (Berger and Luckman 1966; Sampson 1989).

Social constructionists generally consider that each alternative form of social construction invites different consequences or social actions (Ekdawi, Gibbons et al. 2000). For example, until 1990, people who committed minor offences but were considered to be 'mentally disordered' were generally seen as 'difficult' or 'bad' (Butler Committee 1975). As a result of this (and a shortage of medium secure beds), they were often sent to prison. However, following the recognition of a variety of factors, including the vulnerability of such persons when in prison and the fact that prisons only had limited facilities for the treatment of people classed as mentally disordered, there was a move away from seeing them simply as criminals in need of punishment (Home Office 1990). Rather, they are now generally seen as in need of treatment. Whilst they may still be processed by the criminal justice system a change in government policy (Home Office 1990) and legislation has resulted in them being more likely to be disposed of by way of a hospital order or by being given treatment in the community rather than imprisonment. This example demonstrates that constructions of the world or the way people or phenomena are seen may result in some actions being taken, whilst others are excluded. As a result of this social constructionists are frequently concerned with power relations27 because of the implications these have

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[27] See for example the works of Foucault Foucault, M. (1963). The birth of the clinic: An archeology of medical perception. London, Routledge.

concerning the way in which people may be treated and reality defined (Burr 2003).

Finally, social constructionists tend not to consider concepts such as poverty or disability as traits located in the individual. Rather, they consider such concepts as constructions in the wider social and political context, which have emerged as a result of interactions between a variety of social actors (Sampson 1989; Ekdawi, Gibbons et al. 2000). This way of considering phenomena has the potential for giving a voice to oppressed groups (Diversi 2003) and liberating them from oppressive, culturally held assumptions (Gergen and Gergen 2003).

2.2.5. Why choose social constructionism as the theoretical basis for this study?

There are a number of reasons for choosing social constructionism as the theoretical perspective for this study. Firstly, social constructionism does not require one to remain in the boundaries of one discipline (Potter 1996). As someone who has a background in law, socio-legal studies and learning disability nursing, it is important to me to be able to draw on a variety of disciplines as I believe that interdisciplinary working is able to offer a more holistic approach to issues of concern.

Secondly, it is clear from the earlier review of the historical literature (section 1.4.) that 'learning disability' has been viewed and defined in a variety of ways over time and that these differing views of 'learning disability have been shaped by a variety of factors present during those period. Such views and definitions have allowed others to exercise power over men and women with learning disabilities in particular ways, with the result that they have been denied opportunities and freedoms that many people, not so labelled, have come to regard as rights. Likewise, sexuality, as discussed previously (section 1.2), has been viewed in a variety of ways at different periods in history and in different cultures. Given the variance in sexual practices, amongst other things, sexuality should no longer be regarded as a simple biologically or evolutionary determined drive. Social constructionism offers an alternative way of understanding sexuality and its

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, Foucault, M. (1975). Discipline and punish: The birth of the prison. London, Penguin.
and Searle Searle, J. (1995). The construction of social reality. London, Penguin.

relationship with factors such as power relations, morality and economics (Weeks 1986; Daniluk 1998).

Thirdly, whilst some social constructionist writers such as Searle (1995) are very theoretical, many social constructionists are more concerned with what Berger & Luckman (Berger and Luckman 1966:p.27) refer to as 'common sense knowledge' and how that knowledge may be used to a practical end (Gergen and Gergen 2003). Whilst a theoretical interpretation of 'men with learning disabilities' may be of interest to some, this author is more concerned with understanding their subjective reality and giving a voice to this with a view to initiating or promoting positive change.

Additionally, although this text is 'this author's' in so far as he has collated the various ideas contained within it, considered them and then transferred them into writing in his particular style, this process has been shaped by a variety of factors. These include his background as a white British male from the West Midlands, his education in state schools, his (homo)sexuality and the experiences he had in coming to terms with this. Other important factors that have shaped this process have been the interactions he had when working with men and women with learning disabilities, the men he interviewed for this study and with his PhD supervisor. Social constructionism recognises that everyone's experience of reality is shaped by such factors (Ekdawi, Gibbons et al. 2000). Given this, social constructionism sits well with Interpretative Phenomenological Analysis, which is the method selected for analysing the interviews. This also recognises that one can not be wholly objective about a subject. This being due to the fact that we all come from different perspectives and that such perspectives or assumptions shape the research process and thus the results we arrive at (Smith and Osborn 2003).

2.2.6. Summary:

Social constructionism provides one with an alternative view to positivism and many of the things that we may take for granted as given. It draws on a range of disciplines and utilises a variety of methods. Most importantly, it not only enables us to critique positivistic views but also helps us formulate alternative views, which may facilitate positive change.

2.3. Why qualitative research?

Broadly speaking, one has two choices of methodology when embarking on a research study, namely quantitative and qualitative. Quantitative research is associated with positivism and usually focuses on causal relationships which are described in such terms as 'observation', 'quantification', 'verification' and 'prediction' (Kvale 1996; Maggs-Rapport 2001). Although favoured by the natural sciences, it may be criticised, amongst other things, for failing to concern itself with the meaning of experiences (Silverman 2000) or individual consciousness (Giorgi and Giorgi 2003).

Qualitative research is associated with relativism (Kvale 1996) and is more concerned with understanding human behaviour. It is thus more appropriate for researching a phenomenon that has not previously been studied (Barker, Pistrang et al. 2002). As was discussed in the literature review, whilst numerous authors have written about the sexuality of men and women with learning disabilities, much of the writing has been concerned with how to teach socio-sexual education or with negative aspects of sexuality such as abuse. Where studies have been undertaken in relation to the expression of sexuality by women and men with learning disabilities, most have been concerned with the attitudes of formal and informal carers. Few studies have actually sought to explore the experiences of individuals themselves either generally (Atkinson 1988; Atkinson and Walmsley 1999) or more specifically in relation to issues appertaining to sexuality (McCarthy 1998a).

Qualitative research seeks to study a person's thoughts, experiences or feelings in depth and unlike quantitative research, which is highly reductionist in nature and requires people to fit in with pre-decided ideas (Rapley 1995), allows for rich descriptions (Giorgi and Giorgi 2003). Qualitative methods are also more suitable to complex subjects such as sexuality which are difficult to quantify (Flick 2002). Additionally, they may be seen as empowering, allowing the research participant greater freedom than quantitative methods which are more structured (Kvale

1996). This particular consideration is important when interviewing women and men with learning disabilities as they may have had little opportunity to express their views or exert control over their lives (Simons, Booth et al. 1989; Smyly and Elsworth 1997). Finally, there is more likelihood of finding things that the researcher was not looking for than is the case with quantitative methods (Barker, Pistrang et al. 2002).

Although disciplines such as nursing and psychology have generally preferred quantitative research (Rapley 1995; Flick 2002) there does appear to be a growing acceptance of qualitative methods (Henwood and Pidgeon 1994; Maggs-Rapport 2001). Although it is not wholly clear why this may be the case, Kvale (1996) posits the view that the growing acceptance of qualitative methods is due to the change from a economy predominantly concerned with production to one predominantly concerned with consumption and communication. This view is also echoed by Flick (2002) who suggests that the increased use of qualitative inductive methods is the result of rapid social change. Whether or not one concurs with Kvale's (1996) or Flick's (2002) view, the growing acceptance of qualitative studies within nursing suggests that, from a solely disciplinary point of view, it is not an inappropriate choice for a nurse researcher, such as the author of this study.

2.4. Interpretative Phenomenological Analysis (IPA)

There are numerous methods open to those pursuing qualitative studies, including descriptive phenomenology or ethnography. This section outlines why Interpretative Phenomenological Analysis (IPA) was chosen rather than an alternative method.

Barker, et al.(2002) posit the view that there are two main approaches within qualitative research, namely phenomenology and constructionism. The theoretical background to this study is social constructionism, so it was appropriate to select a method that was compatible with this. Although Potter (1996) states that there is no such thing as a constructionist method a number of methods such as critical social theory or radical feminist theory are generally seen as being appropriate to a social constructionist approach. Both of these methods acknowledge the interdependent relationship between the researcher and the participants, the interactive nature of the research process and the production of knowledge. They also encourage a reflexive approach to research (Flick 2002). Having considered a variety of methods, the author of the present study decided to use IPA.

Although it was originally used in Health Psychology and this study is not specifically concerned with health, IPA has been used in a variety of published studies concerned with what may be seen as a disparate range of subjects. For example, it has been used to explore the way in which gay men think about sex and sexuality (Flowers, Smith et al. 1997), various issues relating to genetic technology (Chapman and Smith 2002; Senior, Smith et al. 2002), and the development of identity during the transition to motherhood (Smith 1999).

The stated aim of IPA is to explore the meanings that phenomena hold for participants (Smith and Osborn 2003). It is thus exploratory in nature in relation to the individual's personal perceptions or accounts of the phenomena being studied (Smith and Osborn 2003). However, whilst it seeks to get close to the participant's personal world or obtain the perspective of 'an insider', it recognises that one can not fully achieve such an aim. This being due to the fact that the researcher's own conceptions and experiences are used to make sense of the participant's world. It is precisely this acknowledgement that results in IPA being compatible with a social constructionist approach to the study.

Smith and Osborn (Smith and Osborn 2003) state that there is no specific way to undertake IPA. However, they do offer some guidance on such things as constructing the research question, sample selection, data collection, interviewing and analysis. For example, it is suggested that IPA is a suitable approach for novel situations. In order to use IPA in such situations, they suggest that research questions should be broad and aim to explore the phenomena in detail and in a flexible manner, rather than simply seeking the researcher's predetermined hypothesis.

2.5. Issues appertaining to interviewing women and men with a learning disability.

In the past concern has been expressed that men and women with learning disabilities may not give 'accurate' or 'truthful answers' (Rodgers 1999; Beail

2002). However, such concerns may apply to any information collected by the use of interviews with informants alone. As Giorgi (2003) notes, the information or state of affairs presented to researchers may not be the *actual* state of affairs. For example, people may not remember things accurately or may have perceived the original situation in a different manner to the way someone else might have perceived the same situation. In fact, there is no reason to believe that participants with a learning disability are any less reliable informants about events they have experienced than non-learning disabled individuals (Beail 2002). Additionally, there are a number of reasons for interviewing men and women with learning disabilities about issues of relevance to them rather than seeking to obtain the information from proxies (Minkes, Townsley et al. 1995). Such reasons include the principle of social role valorisation (Kroese, Gillot et al. 1998), concern for the rights of individuals with a learning disability, a concern that those with a learning disability should be empowered to take control of their lives (Walmsley 1991; McCarthy 1998a), and the fact that the individuals are much more likely to 'know' such things as; what they have experienced, learned and the attitudes they hold than carers are (Simons, Booth et al. 1989; Booth and Booth 1996; Prosser and Bromley 1998). That is to say, whilst a third party or proxy may be able to report observable behaviours, they can not know the emotions or thoughts of the individual with a learning disability unless that person has described it to the third party. In which case, the person with the learning disability can equally communicate such matters to the researcher directly, albeit with assistance if necessary.

Most of the principles appertaining to interviewing men and women with a learning disability are the same as those appertaining to interviewing people without a learning disability (Sigelman, Budd et al. 1981; Prosser and Bromley 1998). For example, interviewers should avoid asking leading questions (Clare and Gudjonsson 1993; Shanly and Rose 1993), avoid using jargon that is unlikely to be understood by the participant and should not interview the participant in an environment they find hostile or uncomfortable (Biklen and Moseley 1988; Bradley 2002).

However, due to the fact that those with a learning disability have cognitive disabilities and may find communicating with others difficult (Flynn 1986), researchers should be aware of the possibility of certain phenomena that may occur more frequently in interviews with women and men with learning disabilities than with the non-learning disabled population.

One of the main concerns raised over the years is the issue of 'response bias' (Rapley 1995). This relates to such things as acquiescence, that is when the participant answers 'yes' regardless of the question's content (Matikka and Vesala 1997) and 'nay saying,' that is when the participant answers 'no' regardless of the question's content. Acquiescence is more common than 'nay saying', but both are more likely to occur when the question posed is a 'yes/no' question (Sigelman, Budd et al. 1981; Prosser and Bromley 1998). The phenomenon may occur for a variety of reasons such as the fact that the person being interviewed is trying to please the questioner, the fact that they have been used to living in a hierarchically organised setting or because they do not understand the question (Finlay and Lyons 2002). However, both the extent to which acquiescence is a problem and the question of whether acquiescence is due to individuals' cognitive abilities and education as has previously been suggested (Matikka and Vesala 1997) has been called into question by work undertaken by Antaki (1996; 2002),Matikka (1997) and Rapley (1995). Such work suggests that men and women with a learning disability may not simply be acquiescing as a result of their learning disability. Rather, the perceived acquiescence may be due to situational factors related to the interview such as participants being steered towards a 'correct' answer by interviewers.

Potentially, all question formats may lead to difficulties. For example, multiple choice questions may result in 'recency' effects as the person being interviewed may not remember all of the possible responses and may simply give the last option as their answer (Simons, Booth et al. 1989). However, this is less likely if pictures, photographs or diagrams are used (Sigelman, Budd et al. 1982; Heal and Sigelman 1995). Likewise, although 'either / or' questions, may reduce problems associated with remembering a range of responses such as one is presented with in a multiple choice question, they may also result in the last of the two options being selected. However, they are generally regarded as preferable to 'yes/no' and 'multiple choice' question formats (Sigelman, Budd et al. 1981).

One way of reducing the likelihood of response bias is to use 'open ended' questions. However, it has been suggested that such questions are difficult for men and women with a learning disability to understand and that they achieve a lower response rate than 'yes / no' questions (Sigelman, Budd et al. 1982; Ambalu 1997) (cf. Flynn 1986; Shanly and Rose 1993; Chapman and Oakes 1995; Booth and Booth 1996)

Given the above, the general consensus is that researchers should use a range of question formats (Simons, Booth et al. 1989; Kroese, Gillot et al. 1998), should probe the responses they receive, and ask the participant to provide examples of the phenomenon they are describing in an attempt to improve validity (Rodgers 1999). At the same time, however, one should avoid questioning whether participants are telling the truth and instead focus on identifying and understanding their feelings and perceptions of their experiences (cf. Swain, Heyman et al. 1998; Owen 2001).

Whilst response biases may result in 'invalid' responses, researchers can use appropriate interviewing techniques in order to minimise their likelihood (Finlay and Lyons 2002).

An example of such a technique is asking questions in simple language with which the person is familiar (Booth and Booth 1996; Finlay and Lyons 2002). It is also recommended that abstract concepts are avoided or if this is not possible they are concretised (Dorney 1999). For example, many individuals with a learning disability have difficulties with the concept of time (Booth and Booth 1996), so it may be helpful to get them to relate the occurrence of a particular experience to something more concrete such as a meal time, their birthday, or a festival, the date of which is known (Prosser and Bromley 1998).

Additionally, due to the fact that people may have had negative experiences following their disclosure of information to others previously, it is important that researchers are clear about the nature and purpose of the interviews and what is to be done with the information obtained (Prosser and Bromley 1998). For example, the men that were interviewed in this study may have been told by significant others that sexual touching is 'dirty' and that it should not be spoken about. As a result of this they may have been concerned that if they divulged certain information it would have adverse consequences for them.

Another issue relates to power. Whilst the issue of power imbalance between researchers and participants is applicable in all interview situations, it is particularly important when one is interviewing individuals with a learning disability as they may be unduly influenced by those who they perceive to have a higher status than themselves (Heal and Sigelman 1995; Ambalu 1997; Murphy and Clare 1997). An issue relating to this is that of 'neutrality'. For example, interviewers should be careful not to comment positively or adversely on a participant's answer to a question, they should not offer advice, nor should they limit the scope of potential answers to a question (Antaki, Young et al. 2002).

A further aspect of particular concern in relation to the participation of individuals with a learning disability in research relates to their ability to consent (Brown and Thompson 1997). Although most of the leading cases on consent by individuals with a learning disability relate to consent to treatment, the principles enunciated in those cases are equally applicable when seeking the consent of a person to participate in research. For example, in order for a person to decide whether or not they wish to participate in proposed research, a potential participant currently requires information about the research, must make the choice freely and must have capacity to consent (Wheeler 2003b).[28] Moreover, consent should be regarded as an ongoing concern, rather than a one-off issue only requiring consideration at the commencement of the research process (Swain, Heyman et al. 1998).

One particular concern of mine[29] was my role. On the one hand, I wished to approach the research solely as an independent researcher. To do so required the establishment of rapport and the encouragement of personal and emotional expression. On the other hand, Kvale (1996) has argued that researchers should not allow an interview to turn into a therapeutic situation. As a registered nurse I was bound by the Nursing and Midwifery Council's Code of Conduct (2002) and the guidance contained in 'Practitioner-client relationships and the prevention of

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[28] The legal requirements re consent to participate in research may change in the future should the **Mental Capacity Bill 2004** be enacted.

[29] For the remainder of the methodology section, the author uses the first person rather than the third person. This is due to this section being reflexive. Additionally, it acknowledges the fact that author has interpreted the findings. Although writing in the first person may not be traditional in academic writing, Jonathan Smith in a personal communication states that both styles are acceptable and that within a PhD it is possible to, '*...move between the two voices*' Smith, J. A. (2004a). Re use of 3rd or 1st person. P. Wheeler. London, Personal Communication.

abuse' (Nursing and Midwifery Council 2002a) which provides that nurses should always act in the best interests, not only of their clients, but of the wider community and that they have a duty to act to protect persons from risk. Given these possibly conflicting roles, I was somewhat apprehensive, to say the least, about undertaking the interviews. For example, I was concerned that participants may have made disclosures that implied either that they were being abused or were themselves abusing other vulnerable persons. In either case, my duty as a nurse may have been in conflict with the role of the independent researcher and its 'demand' for confidentiality (McCarthy 1998a).

2.6. Procedure:

2.6.1. Method of data collection.

The next choice requiring my consideration was the method of data collection. I dismissed a number of data collection methods almost immediately. For example, I felt that observation would not have been appropriate to the subject matter of the study, additionally it would have been very time consuming and intrusive. Other methods were dismissed due to the participants having learning disabilities. For example, although men and women with learning disabilities are not a homogenous group, many have difficulties writing, so a written diary or self report would have been inappropriate. I also considered the use of attitude tools. However, whilst there are a number of scales relating to sexuality that have been designed for, or adapted to be used with men and women with learning disabilities, I chose not to use them. There were a number of reasons for this. Firstly, unless participants are involved in their design, the use of scales allows participants little control over the research process. Rather, they are expected to match their experiences and feelings to statements that may not be relevant to them. Secondly, even the most respected of the tools designed or adapted for measuring sexual knowledge and attitudes of people with learning disabilities appear to have a number of problems, such as being time consuming, difficult to administer and including value-laden items (McCabe, Cummins et al. 1999). Additionally, they do not fit well with either qualitative methodology generally or, more specifically, with IPA.

Whatever method of data collection one selects, it clearly needs to be appropriate to such factors as the research question, the participants and the chosen method of analysis (Giorgi and Giorgi 2003).

Following consideration of such matters I chose to use semi-structured interviews as the main means of data collection as these were appropriate to the method chosen, namely Interpretative Phenomenological Analysis (IPA), they were relatively flexible, were amenable to modification as they progressed and allowed both myself and the participants to adopt a more natural conversational type style, which hopefully assisted in the building of rapport and resulted in my being provided with richer material (Chapman and Oakes 1995; Booth and Booth 1996; Kroese, Gillot et al. 1998). Furthermore, although the interviews clearly had a researcher led agenda (Banister, Burman et al. 1994) they also had the potential of providing participants with greater control over the interview situation (Robson 1993; Smith and Osborn 2003).

2.6.2. Topic Guide

As a number of authors note, no researcher approaches a research topic without previous consideration of the matter, though they may actively seek to avoid imposing their perspective onto the data (Henwood and Pidgeon 1994; Altheide and Johnson 1998; Boyatzis 1998; Charmaz 2003). As has already been acknowledged in section 2.2.5. (concerning social constructionism), I did not come to this research with a blank mind. Rather, I approached the topic having my own perspectives and assumptions which resulted from my life experiences. For example, as a youth growing up I was aware that not only was my homosexuality frowned upon by society, but that for me to express my sexuality through a sexual relationship was unlawful. These factors caused me to feel that I could empathise with another group of individuals, namely men with a learning disability, whose expression of sexuality was restricted in similar ways as a result of the provisions of the Sexual Offences Act 1956 and societal attitudes. Additionally, my experience of growing up as a homosexual was that I was perceived as 'less of a man' than heterosexual males. Again I felt that this could result in my being more empathetic towards men with learning disabilities who may also be seen as 'less than real men' (Shakespeare, Gillespie-Sells. et al. 1996).

Although I could have conducted the interviews without a topic guide, the production and use of such a guide is recommended generally in qualitative studies (Flick 2002) and specifically in IPA studies (Smith and Osborn 2003). Additionally, I found it helpful when I sought ethical approval as presenting the guide to the ethics committee provided them with a clearer understanding of the nature and format of my study.

I composed a topic guide which related to reasons why men with learning disabilities might not express their sexuality (See Appendix 1). The headings chosen for the guide evolved from the literature contained in section one of this dissertation and from my personal experience in working with men and women with a learning disability. Additionally I was, no doubt, influenced by a variety of other factors such as my, then, supervisor, Michelle McCarthy. The main headings were: 'Opportunities of meeting people or making friends'; 'Self perception'; 'Knowledge and attitudes about sexuality issues'; 'Intimate relationships' and 'Hopes for the future'.

Clearly, the questions asked shaped the research process and thus the results arrived at (Banister, Burman et al. 1994; Charmaz 1995). However, the topic guides were discussed with focus groups prior to them being used in individual interviews, as discussed below in section 2.6.6. in order to ensure the topic headings were relevant and of importance to similar men to the participants. Additionally, as the results section demonstrates and as can be seen in the transcripts (Appendix 2), participants introduced other matters into the interviews. Moreover, the order of the questions was not rigidly adhered to, with the result that some participants discussed the topics in a different order to that anticipated.

2.6.3. Ethical Approval

The subject matter of the study is one that would generally be referred to by others as 'sensitive' due to the fact that it relates to sexuality (Lee 1993; Owen 2001). In the past researchers have tended to opt out of studying sensitive topics (McCarthy 1998a), possibly as a result of the ethical, legal and political aspects of research having become more salient than was previously the case (Lee 1993). However, as Lee argues, I believe that 'opting out' of such research is an evasion of responsibility on the part of researchers. Additionally, McCarthy (1998a) posits the view that avoiding sensitive topics ignores the possible benefits that participants may obtain from participating in such studies. Rather than avoiding such issues, it is arguable, therefore, that it is important that researchers find ways of dealing with subjects that may be considered sensitive.

Given the sensitive nature of the subject being researched, I wished to ensure that the research was conducted in an ethical manner (Swain, Heyman et al. 1998). Additionally, the Tizard Centre requires would be researchers to submit a research proposal for consideration by the Tizard Centre Ethics Committee. This requires an outline of the nature and purposes of the project. It also requires specific consideration of whether participants will be paid, possible risks to participants, intended feedback to participants and anticipated difficulties, in particular in relation to possible power imbalances. It requests that the researcher discuss how the research meets the four main ethical principles of research, namely: non-maleficence, beneficence, autonomy and justice. Finally, it requests that the researcher discuss issues relating to consent. The ethical review check list was submitted to the ethics committee (see Appendix 3) and I attended the committee's meeting in order to answer any questions the committee might have had. The committee, although they made a number of suggestions as to the research, approved the submission in July 2002. Minor amendments were made in line with the suggestions of the committee and my PhD supervisor at that time approved these changes at the end of October 2002.

One concern was that the subject of the interviews meant it was possible that both the participants and the interviewer might become distressed (Swain, Heyman et al. 1998). For example, in the event that a participant disclosed unresolved sexual abuse the participant may be distressed by recounting the abuse and the interviewer may have become distressed as a result of being unsure about how best to respond. In an attempt to address such concerns I discussed them with my PhD supervisor and it was agreed that my supervisor would offer me 'clinical supervision' if I sought it.

2.6.4. Recruitment of Participants

In selecting potential participants purposive sampling was used. That is to say, participants who would be able and willing to share their experiences, and were also convenient (Silverman 2000) were actively sought. In short, an attempt was made to recruit participants who would be 'good informants' (Flick 2002). This decision was initially based upon practical considerations. The most pressing of these was the limited time and resources available to me. Additionally, however, purposive sampling is the form of sampling recommended by Smith (Smith and Osborn 2003) for use in IPA. To this end, I contacted a number of self-advocacy and similar organisations in South Wales. This was in order to outline the proposed research and enquire whether members of those organisations would be interested in participating.

The reason for choosing such organisations was that members of the organisations might be more able to self advocate, describe their experiences and express their opinions and feelings than other men with learning disabilities. This was seen as having at least two implications. Firstly that it made it more likely that potential participants would feel able to decline to participate and /or answer questions with which they felt uncomfortable. Secondly, I thought that interviewing such individuals was likely to provide a more positive view of the experiences of men with learning disabilities given that members of such organisations are arguably better able to advocate for, or assert their desires than those who have less experience of self-advocacy.

Clearly, the purposive nature of the sample means that the findings of this study are not directly generalizable to all men with learning disabilities (Silverman 2000). However, I believe that they may be extrapolated to the wider population of men with learning disabilities as a result of the above considerations.

Smith and Osborn state that there is no optimal sample size for IPA studies (Smith and Osborn 2003). They note that studies have been published using samples of one, four, nine and fifteen. However, whilst potential researchers are not told how many interviews they should undertake, studies using IPA generally involve a small number of participants. This is for a variety of reasons including the time the method takes to complete. This present study involved twelve participants. The choice of this number was not scientifically based. As a result of 'snowballing' interest in the study (Lee 1993) by members of the groups, I was presented with a larger number of volunteers than might normally be included in an IPA study. Although I wished to ensure that there were sufficient participants in order to investigate differences and similarities between the participants' experiences, I also wished to avoid having an excessive and unmanageable amount of data (Silverman 2000). As a result of this, I did not undertake interviews with men who expressed willingness to participate towards the end of the interviewing phase of the study.

2.6.5. Overcoming the concerns of 'gatekeepers'

When discussing the proposed research with other researchers, I found that many people suggested that I was likely to have difficulty in accessing a sample due to the fact that 'gatekeepers' may be unwilling to allow access to potential participants because of the nature of the subject. Additionally, as part of my preparation for the research, I read literature appertaining to the access process. One of the more helpful discussions of ways of overcoming the concerns of gatekeepers may be found in chapter 7 of Lee's (1993) book. As a result of the dichotomous nature of advice and information offered I approached this issue with some trepidation. Surprisingly, I was to find that overcoming 'gatekeeper concerns' was not a major hurdle. Rather, what was more difficult was arranging the actual interviews, as a result of participants' occupational activities, lack of transport and a general reliance on others in order for them to attend.

2.6.6. Focus Groups:

Prior to commencing the individual interviews, I facilitated two focus groups. The first was comprised of three men who belonged to a self advocacy group. The second was comprised of four men from another self advocacy organisation. The main aim of these focus groups was in order to check that potential participants felt that the subject matter was of interest and relevance to their lives, as is recommended in situations where the questions are not directly raised by individuals with a learning disability (Smyly and Elsworth 1997; Rodgers 1999). It also provided me with the opportunity to practice using the topic guide, and assess the accessibility and appropriateness of the information sheet (Appendix 4) and consent forms (Appendix 5). Interestingly, although their ability to read text was limited, the men in these groups were not in favour of the use of pictures or symbols on the information sheets, as had been suggested by the ethics committee, as they felt this was 'childish'. They did, however, agree with other suggestions of the ethics committee, namely that the font size would benefit from being larger and that tick boxes should be included on the consent forms.

A further reason for holding the two focus groups was that it has been suggested that focus groups are valuable in exploratory work (Fraser and Fraser 2001), are more appropriate than in-depth 'one to one' interviews when studying 'taboo' subjects (cf. Owen 2001; Flick 2002) and that they encourage participation by those who might be reluctant to be interviewed on a one to one basis (Owen 2001). However, I found the facilitation of these interviews difficult as the participants appeared unused to group work. For example, they looked to me for 'permission' to speak and did not generally offer opinions contrary to those offered by others in the group. On a future occasion, I would undertake preparatory group work with potential participants as recommended by Dorney (1999). There may have been other reasons that the group interviews were not particularly successful, as other people have undertaken focus groups with men and women with learning disabilities successfully (Fraser and Fraser 2001). One reason may have been the size of the groups, in that they were smaller than most focus groups generally are (Krueger and Casey 2000; cf. Fraser and Fraser 2001). Another may be that the members were known to each other which may have inhibited their discussing the subject. A further possibility is that men are less suited to participating in focus groups than women due to the fact that men do not generally have an established tradition of sharing personal information with other men (Owen 2001). Additionally, although I had experience of small group teaching I had little experience of facilitating focus groups and I may simply have lacked the requisite skills (Owen 2001). However, despite the focus groups having limited success, there were a couple of occasions when answers given by one member of a group appeared to stimulate other members of the group to relate similar events.

2.6.7. Demographic details of Participants in the in-depth interviews:

A total of twelve persons participated in individual interviews. All twelve participants were male and were members of one of three self-advocacy type organisations for people with a learning disability. They varied in age from 16 to 42 years and their mean age was 25 years and six months. All lived in towns in semi-rural South Wales. However, they varied in respect of the type of accommodation in which they lived. Nine lived with family members, one lived in supported accommodation and two lived alone. They also varied in respect of their occupation as will be discussed in part three of this dissertation.

Whilst no attempt was made to ascertain the degree of learning disability participants had, my experience suggests that they would all be diagnosed as having a mild to moderate learning disability. All were in receipt of some disability living allowance and had either attended special schools or were currently using services provided for people with a learning disability.

2.6.8. Interview Procedure

I was very aware of the fact that research interviews are not an interaction between two equal partners (Kvale 1996) and of the fact that men with a learning disability may be more prone to the influence of power imbalances than non-learning disabled men (Booth and Booth 1996; Ambalu 1997). The interview procedure was arranged in such a way as to attempt to overcome such issues. Additionally, I dressed casually and presented myself to the, would be, participants as a student, rather than as a learning disability nurse or lecturer. This was because I felt that presenting myself in this way, that is, as a 'learner' rather than an 'expert' or someone in authority would help to reduce possible power imbalances. This approach appeared to be helpful as a number of the participants were able to associate themselves with being a student and described their experiences of college to me.

I met would be participants prior to commencing the interviewing, in order to discuss the purpose of the interviews and to provide them with a briefing about the likely format of the interview. These meetings and the subsequent interviews were conducted in private rooms within accommodation used by the organisations. This was for two main reasons, firstly, it is generally recognised that people feel more comfortable about answering the questions posed if the interview takes place in a familiar setting (Smith and Osborn 2003). Secondly, it is generally thought preferable to study phenomena in their natural environment rather than in an artificial setting (Giorgi and Giorgi 2003). As noted previously, it would not have been appropriate to conduct an observational study. However, it was hoped that interviewing people in surroundings with which they were familiar would reduce any power imbalance, in so far as I was a guest of those participating in the research. Additionally I hoped that it would avoid some of the difficulties associated with undertaking research outside of a person's natural environment.

During the preliminary meeting, would be participants were given an information sheet (appendix 4) and were advised that they should take time to consider whether or not they wished to participate. They were also encouraged to discuss their possible participation with significant persons such as their parents, carers or advocates.

On meeting with each individual who had shown a willingness to participate, I provided him with a briefing, once again outlining the nature of the research and the fact that I wished to record the interview. At this time, the consent form (Appendix 5) was presented to the, would be, participant. This was read aloud and explanations were provided where necessary.

An audio recording of the interviews was made using a mini-disc recorder and boundary microphone. The reason for choosing a mini-disc recorder rather than an audio-tape recorder was that sound quality was better and as a result transcribing was less difficult. Additionally, the discs could record 148 minutes of data. This avoided the need to change tapes part way through the interview, which may have been an intrusive distraction. Clearly, the use of an audio recording has limitations such as the fact that it does not record non-verbal data (Giorgi and Giorgi 2003; Smith and Osborn 2003). However, I felt that video-taping the interviews would be too intrusive and complex. However, in an attempt to record some of the non-verbal data, field notes were made immediately after the interview. Additionally, the recordings were transcribed shortly after the interviews had been undertaken in order that they were still 'fresh' in my mind as recommended by Booth and Booth (1994) and Plummer (1995).

The first part of the interview was spent trying to establish a rapport with the participant and simple questions were asked with a view to helping them feel at ease (Williams 2003), build an atmosphere of trust and co-operation (Walmsley 1991) and also in order to provide me with an idea of the participant's comprehensive and expressive ability.

More sensitive topics were discussed as the interviews progressed and the participants had become more comfortable both with myself and the interview process. This is generally accepted as an appropriate way to sequence interviews (Lee 1993; Smith and Osborn 2003).

I sought to ask questions in a manner that followed the guidance provided about question formats by those who have studied issues relating to interviewing women and men with learning disabilities as discussed in section 2.4. In particular I followed the guidance given by O'Hara and Sperlinger (1997) and Robson (1993).

Although I selected IPA as my chosen method, the interviews may be seen as different in comparison to other IPA studies. This is due to the fact that in this study, I used more prompts than might ordinarily be found in IPA studies. This was because participants were not generally forthcoming in discussing topics when presented with open questions. This may be due to the fact that the participants had a learning disability as discussed above (section 2:4). However, whilst it is expected that interviews using IPA will use as few a prompts as possible (Smith, Flowers et al. 1997), it is recognised that even non-learning disabled participants may require prompts in order that a satisfactory response to the question is obtained (Smith and Osborn 2003). In seeking to overcome the fact that a number of the participants were not very forthcoming when asked 'general' questions, I sought to use prompts that were not leading, that were appropriate to the participants' comprehensive abilities and that were generally open (Booth and Booth 1996). I was also fortunate enough to be able to attend the 5th annual IPA conference in Plymouth in June 2003. During this, one of my transcripts was used in a workshop about analysing transcripts. Whilst it was noted that I had used more prompts than might ordinarily be the case, it was felt by both the facilitator and participants that this was necessary in interviewing men with learning disabilities.

At the end of the interview I invited participants to ask questions of me in order to give them the opportunity to discuss any issues that had not been discussed or that had caused them concern. They were then thanked and given five pounds in appreciation for having given up their time.

Interviews varied in length between 26.58 minutes and 92.7 minutes, with the average duration being 49.89 minutes.

2.7. Analysis of the transcripts

As with other aspects of IPA, the way in which one analyses a number of cases is not specified. That is to say that Smith and Osborn (2003) suggest that one can either use themes that emerge from the first transcript in order to analyse further interviews or one can analyse each transcript individually without reference to the themes that emerged from previous transcripts.

Having transcribed and anonymized the interviews, I discussed them with my PhD supervisor in order to decide which of two approaches to follow. They were whether to code all of the transcripts in depth or whether to transcribe one of them in depth and then look for the themes present in the first transcript in the remainder of the transcripts. As with other aspects of the study, a compromise was made. On the one hand, I wanted to give voice to each of the individual participants. On the other, time and other resources were limited. I decided to analyse four of the transcripts from 'scratch', that is without reference to themes from other transcripts. The themes from these four interview transcripts were then sought in the remaining eight interview transcripts. The four transcripts selected were those of participants' number two, five, eight and ten. The choice of these was not related to the frequency with which particular themes appeared to occur at first reading. Rather, they were selected on factors such as the age of the person, whether or not they had experienced relationships or were currently in a relationship, whether they were able bodied or not, and the richness of the interview. Such a choice is in line with the suggested practice described by Smith and Osborn (2003) in their chapter on IPA. In brief, the four participants' transcripts selected for in-depth analysis were chosen for the following reasons: Participant one was selected predominantly because he was the only individual amongst the participants who was in a long term relationship. Participant five was selected as he was older than most of the other participants, and raised interesting topics such as possible abuse and transgender. Additionally, the use of prompts in this interview was minimal. Participant eight was selected as he was one of the younger participants and because he raised interesting issues around socio-sexual education and control. Finally, participant number 10 was selected as he was the only wheelchair user amongst the sample and raised interesting issues relating to interpretation of sexual activity.

Analysis was undertaken in the manner described by Smith and Osborn (2003) and Larkin (2003). In brief, transcripts are read a number of times in order for the researcher to become familiar with them. Notes are then made of anything that is interesting or significant. Once this has been done, the researcher returns to the beginning of the transcript and seeks to record emerging theme titles. The researcher then looks for and seeks to make sense of the connections between these themes. As themes emerge and become more abstract, the researcher checks the transcript in an attempt to ensure that what the person actually said does fit in with the researcher's interpretation of what was said. A table of themes is then produced whereby themes that have emerged are put in a coherent order and super-ordinate themes are defined. The fifth stage of the process is to construct a final table of super-ordinate themes upon which the researcher will focus. At this stage, the researcher will return to earlier transcripts to look for themes that emerged from later transcripts. The final stage of the process of IPA is the writing up stage during which the themes are translated into a narrative, explained and illustrated with verbatim extracts from the transcripts to support the argument being presented. These 'results' are discussed in relation to relevant, extant literature.

In practice, I sought or looked for what Boyatzis (1998) referred to as, 'the codable moment'. That is to say I needed to recognise that 'something' was important. Having seen this, I then sought to consistently or reliably code it as that 'something'. The codes were then developed into themes which were amenable to interpretation. The coding was undertaken on a line by line basis, which, although time consuming, did force me to think carefully about the material (Charmaz 1995).

I chose to use NVivo as a tool for coding the transcripts rather than cut and pasting as is recommended by some authors (Plummer 1995). NVivo allows a researcher to code in a 'top down' manner, that is, applying codes or themes that have been previously decided upon to the data. Alternatively a researcher may code in a 'bottom up manner', that is to say by coding 'nvivo' on a line to line basis. Given the exploratory nature of the current study, the latter option was chosen in order to code the first four transcripts. The remaining transcripts were then coded in the former manner with me looking for, and applying, the codes present in the first four interviews to the remainder of the transcripts.

In an attempt to ensure consistency and reliability in coding, having coded the transcripts, I requested that my PhD supervisor look at them and give his views on the attributions that I had ascribed them (Boyatzis 1998; Smith, Jarman et al. 1999). My supervisor concurred with the attributions and only suggested the inclusion of one further theme that was present in two of the transcripts that were analysed using the themes obtained from the first four transcripts. The need to do this clearly demonstrates that one danger of using a 'top-down' approach to coding is the possibility that pertinent data may be missed.

It has been suggested by some writers (Flick 2002; Williams 2003) that in order to ascertain the validity of one's findings one should return to the participants to ascertain whether they agree with the researcher's findings. However, this was not recommended by Jonathan Smith (2004) who, in response to a question on this subject in the Yahoo IPA Discussion Forum, argued that the more interpretative one's work is the less appropriate participant validation becomes. This is due to the fact that the researcher's interpretation is not necessarily one which the participant would share or feel able to own. This phenomenon may arise due to the fact that the interpretation emerges from the analytic dialogue between researcher and participant and thus exists separately from the two. Rather than use participant validation, he, along with others suggests the use of independent audit (Flick 2002; Smith 2003a) a process I sought to follow.

2.7 The use of IPA with people with learning disabilities – a summary of some of possible advantages and disadvantages.

The use of IPA with men and women with learning disabilities is of itself 'groundbreaking'. At the time this study was undertaken, I could find no published research which had used this method in undertaking research with people with a learning disability.

There are a number of clearly positive aspects to its use with men and women with learning disabilities. Firstly, like other qualitative methods, it allows the voice of the participant to be heard. Given that people with learning disabilities have in the past often been denied a voice (Walmsley 1991), this is a positive reason for the use of IPA. Additionally, it allows the participant greater control than is possible using such methods as administered questionnaires. Thirdly, as discussed in section 2.4., whilst allowing a researcher to get close to the participant's personal world, it recognises that the researcher makes use of his or her own knowledge, experiences, and attitudes to interpret the information given by the participant (Smith and Osborn 2003). Such honesty is important and should assist in the empowerment of men and women with learning disabilities who may previously have had other's views imposed upon them.

However, there are also a number of issues arising from its use that may be perceived as less positive and requiring of further exploration. Firstly, whilst some guidance is offered as to how IPA may be undertaken, there is no specific way to undertake IPA (Smith and Osborn 2003). Whilst this may allow for flexibility and the development of the method, it may also be viewed as somewhat unhelpful in that it may result in confusion as to what exactly IPA is and how it should be undertaken. Secondly, although the promotion of open questioning (Smith, Flowers et al. 1997) may avoid such problems as acquiescence it is likely to restrict use of the method to individuals with a mild learning disability. Additionally, when IPA is used in novel situations it is important that research questions be broad and avoid seeking the researcher's predetermined hypothesis. Given that men and women may have difficulty in understanding 'open-ended' questions (Ambalu 1997) it is particularly important that the interviewer is careful not to use leading questions when offering prompts. One possible method of overcoming this issue is to hold focus groups prior to preparing the topic guide to ensure that the topic guide focuses on issues perceived as important by a sample similar to that taking part in the one to one interviews, rather than on those thought relevant by the researcher. Thirdly like many other qualitative approaches, IPA is fairly time-consuming. This is likely to result in small sample sizes which, amongst other things, such as the purposive nature of samples, prevent findings being generalised to a wider population.

Given the lack of published studies using IPA in research with men and women with learning disabilities, it is not currently possible to comment on its overall appropriateness or otherwise. Rather, what is needed is for more such studies to be undertaken and carefully documented in order that the use of this method with women and men with learning disabilities may be properly evaluated.

Part Three: Results and discussion:

3.1 Introduction:

This section of the dissertation provides the reader with an overview of the super-ordinate themes that emerged from the study. These themes are then discussed individually, using verbatim extracts from the interviews to exemplify them (Flowers, Smith et al. 1997; Smith, Jarman et al. 1999). They are also discussed in relation to extant literature.

3.2. Super-ordinate themes:

In coding the initially selected four interview transcripts, namely those of participants two, five, eight and ten, one hundred and thirty initial themes or nodes were identified as can be seen in appendix 6. These themes were then sought in the remaining eight transcripts. Connections were sought amongst these initial themes and, where appropriate, initial themes were clustered together in an attempt to produce super-ordinate themes.

There were fourteen super-ordinate themes identified from the clustered initial themes. They were: 'Living arrangements and sense of place', a theme which includes five sub-themes. These relate participants' actual and desired living arrangements to their home context and their perceived role in the family; 'Occupation and occupational aspirations', which is comprised of four sub-themes relating to the nature of participants' occupation and any aspirations they expressed in relation to future occupation; 'Finances and sense of agency' includes seven sub-themes all of which relate to participants' finances and the impact finances had on their sense of agency; 'Community Participation and Inclusion', is comprised of seven sub-themes that are concerned with leisure and how it was accessed; 'Attitudes to, and experience of platonic relationships', is comprised of three sub-themes which are concerned with platonic relationships; 'Sense of self', contains eleven sub-themes relating to participants' perception of themselves; 'Understanding others through being male', is comprised of seven sub-themes all of which relate to the way in which the participants understood or perceived other phenomenon such as women or homosexuality; 'Socio-sexual education' is a theme which includes ten sub-themes, all of which relate to the socio-sexual education participants received, for example, the nature of the information, where they received it and the importance they attached to it; 'Understanding of issues around sexuality' includes eleven sub-themes. They are concerned with the understanding that participants' have of a variety of issues such as law, consent, and concepts such as love and attractiveness; 'Sexuality: attitudes and behaviour' contains seven sub-themes relating to participants' attitudes and behaviour towards a variety of issues such as whether they perceived themselves as sexual beings and their attitudes towards pornography; 'Experience of and aspirations towards intimate relationships', in which there are fourteen sub-themes is concerned with the experiences participants have had of intimate and personal relationships and their expressed aspirations towards such relationships; 'The context of parenting by men with learning disabilities', is comprised of seven sub-themes that consider the issue of parenting by men with learning disabilities from a number of perspectives; 'Others' attitudes to intimate and personal relationships', includes six sub-themes concerned with the attitudes of others, such as carers, towards the participants having intimate relationships with others; Finally, the super-ordinate theme 'Personal experience of bullying and abuse' is comprised of three sub-themes concerned with the participants' vulnerability to bullying and abuse.

Amongst the fourteen super-ordinate themes, one can also identify a number of threads running throughout them such as 'agency' and 'autonomy'. These threads will be discussed in the context of each super-ordinate theme.

3.2.1. Living arrangements and sense of place:

This section of the findings and discussion is concerned with the places in which participants live and the perceived effects this has on their ability to act as autonomous individuals.

3. 2.1.a. Living with family members:

Nine of the twelve men lived with family members. Two of these lived with their father, one lived with his mother, one lived with a sister and the remainder of the nine lived with both parents.

A number of issues were discussed concerning living arrangements including their relationships with others at home, their perceived ability to act as autonomous individuals, whether or not they felt able or sufficiently comfortable to receive visitors, and whether they felt able to give potential acquaintances and friends their family's telephone number.

Only one of the participants clearly expressed the view that he was happy living at home, and even this was in relation to this being perceived as preferable to living in residential accommodation where he had been bullied.

On the other hand, a number of participants described difficulties in their relationships with their family and six of the nine expressed the view that they would like to live independently as will be described later. Although reasons why participants experienced difficulties living at home were not explored in any detail a number of them related such difficulties to the fact that they perceived themselves as not being allowed to grow up.

3.2.1.a.i. Being allowed to grow up

Although one individual living at home was given a front door key in order to come and go as he chose (so long as he telephoned his parents to advise them of his likely time of return), a number of participants living with family felt that they were treated as children and were not recognised as being adults. For example, participant ten who was twenty-five years of age said:

<u>P 10. Para. 49</u>

P10 *What Mam can't get used to and I'm not criticising her, is Mam can't get used to me growing up to fast.*

This, and particularly 'mothering' behaviour annoyed him:

<u>Para. 173</u>

P10 *Sometimes it makes me angry, cause I feel, how can I say, Mam's always back and forth and says 'do you want a drink', 'do you want something to eat', now I'm not criticising Mam now cause me and Mam are different ages. I mean I'm 25.*

Likewise, participant twelve expressed the desire to move away from his father, but perceived his father as viewing him as incapable even if supported:

P 12. Paras. 331-334:

Int. *Right. So why do you think your dad doesn't want you to leave?*

P12 *Cause of the way I am, cause of my disabilities.*

Int. *He doesn't think you can manage?*

P12 *Um.*

Int. *What about living somewhere with some staff support?*

P12 *That was what was going to happen but my dad said no. So I lost that one.*

One aspect of growing up and feeling a sense of place in one's home is being able to bring friends back, either to visit or stay.

3.2.1.a.ii. Taking people home:

Many of the participants were able to bring male friends back to their home and were able to entertain them as visitors, particularly where the friend was previously known to the parents. However, many participants did not feel able to take female friends or girlfriends home. For example, participant one did not feel that his parents would like him taking a potential girlfriend home:

P1. Paras. 118-124:

Int. *Are your mum and dad happy about you bringing friends home?*

P1 *Yeh*

Int. *What about if you met someone that you found really attractive and you fancied and you wanted take them home?*

P1 *I don't think my parents would like it - just normal friends*

Some participants also felt able to have friends stay with them overnight, though this did not appear to be a regular occurrence. However, other than one participant (participant six) who thought that his parents would be 'ok' about him bringing a girlfriend back to the house, most expressed the view that they would feel uncomfortable about taking a girlfriend back to their home. Reasons for this varied. For example, one participant (participant eleven) started to suggest that the reason his girlfriend did not stay was because his room was not tidy. However, it later transpired that other people had stayed overnight and that it was more likely that his girlfriend was unable to stay because his father disliked her. Another, (participant ten), felt that he would not be allowed any privacy and would be questioned by his mother.

A further aspect of having a sense of place within the home is being able to give your phone number and, or address, to people you meet and may like to develop a friendship with.

3.2.1.a.iii. Giving home address and telephone number to new acquaintances and use of phone

Participant ten did not feel able to give his home telephone number or address to people due to a lack of privacy. However, most of the participants felt comfortable giving their telephone number to new acquaintances and believed that their families would be accepting of this. For example, participant seven, when asked whether his parents would complain about him receiving phone calls from strangers said:

P7, Para. 63

P7 *No, they'd be alright. They want me to make friends and stuff, they do.*

He was, however, concerned that people might make 'funny phone calls'. Although other participants were not concerned with receiving 'funny phone calls' they appeared aware of possible dangers of giving strangers both their telephone number and address. Many expressed the view that although they would give someone they had recently met their telephone number, they would not also provide their address as can be seen in the following extract from the interview with participant six:

P6, Paras. 75-77

Int. *Yes. Say you go somewhere and you meet someone and you think they are really attractive or you think they are really nice people and you'd like to see them again, how do you / what do you do? Do you give them your phone number or address or?*

P6 *Give my phone number not the address.*

Int. *Right.*

P6 *But they / eventually if they get to know you well then give your address, but not just yet, not just now, only give your phone number until you get to know the person.*

Int. *Is that because it's safer or...*

P6 *Yes, just in case they might go rob the house and things.*

Some of the participants possessed mobile phones. In some cases this clearly enhanced their independence. For example, participant one did not think his parents would approve of him giving the home phone number or address, but felt able to give people his personal mobile telephone number.

P1, Paras. 54 - 60

Int. *So if you met somebody that you really liked ... um ... while you were out in the pub or club would you give them your phone number?*

P1 *Yeah, well only a person I can trust someone who won't like give it to no-one else. (unclear) Like say my house number I don't want everyone to know it (unclear) my parents wouldn't like it - you only give your house number to a person you can trust.*

Int. *Would you give them your address as well?*

P1 *No - probably not cause (unclear)*

Int. *Your mum and dad wouldn't like it?*

P1 *No - If I was living on my own it would probably be all right ... if I was living on my own, like sharing a flat with my friend or whatever, like, if I was living independently.*

Possession of a mobile telephone was not, however, necessarily liberating. In the case of participant ten, this was due to the high call charges and his limited income. In relation to other participants, it appeared that whilst facilitating their increased independence, the possession of a mobile telephone was also related to their family's concerns about their vulnerability. For example, during the interview with participant twelve, who described the fact that he was not allowed out other than to attend a group on a Saturday, he was called on his mobile telephone by his sister who was checking to see what time the group finished in order that she could collect him.

3.2.1.a.iv. Parental Concerns about vulnerability

A number of the participants expressed the view that parental concerns about vulnerability had a restrictive effect upon their lives. For example, participant ten felt that his mother's concern about his alcohol consumption resulted in him losing his last girlfriend:

<u>P10, Paras. 290 – 296:</u>

Int. *So, your last girlfriend, can you remember how long you were going out with her, was it a couple of weeks, a couple of months?*

P10 *It was back in the summer it was, yes ... Mam didn't help, she didn't give her a chance.*

Int. *What do you mean, 'Mam didn't give her a chance'?*

P10 *() Mam reckoned she was encouraging me to drink (unclear).*

Int. *To drink?*

P10 *To drink more, you know shorts and all that.*

In some cases such concerns about vulnerability had been internalised by the participants themselves as is shown in the following extract from the interview with participant eight:

<u>P8, Paras. 73-76:</u>

Int. *So you wouldn't go out on your own?*

P8 *Nah.*

Int. *Ok. Is that because you feel worried or because your parents feel worried about things...*

P8 *Both me and my parents feel worried about it because, um, 'cause, when we um, when we go away I never go down there because I think there is a chance I could have my drink spiked and I never take the opportunity, you know, if they all go down to B (local town) I always stay back an all that.*

3.2.1.a.v. Preferred living arrangements:

As mentioned previously, six of the nine participants living with family expressed the view that they would like to live more independently. One (participant two) described how this was in the process of happening and further described the fact that his father was supporting him in this venture. Some felt that this would be possible given appropriate support. Others, however, that it was not possible in the immediate future. For example, participant eleven felt that he would be unable to do so whilst he remained indebted to his father for catalogue goods which his father, as the catalogue agent, had sold him. Still others felt that attaining such independence would not be possible so long as their current main carer was alive as can be seen in the following interview extract:

P12, Paras. 331 – 334;

Int. *Do you think he'll (his father) ever agree to you going out and living on your own?*

P12 *No.*

Int. *No? () Do you think you could change that at all?*

P12 *I don't think I could. He won't even let me go outside the house at the moment. The only time he'll let me go outside the house is on the farm or with my cousins.*

3.2.1.b. Living in shared accommodation:

Only one of the participants, (participant five) lived in shared accommodation. He lived with another male with learning disabilities. They received daily support in the morning and evening. Whilst the question of whether he felt as though he was treated as an adult by his carers was not explicitly discussed, similar issues relating to sense of place as discussed with those participants living with their family were discussed with him.

3.2.1.b.i. Taking people home:

Participant five had received conflicting information as to whether or not he should take people home. At a policy level, it would appear that he was encouraged to view the house as his home as shown in the following extract:

P5, Paras. 82-83;

Int. *You said that you can stay out late if you want, there's no problem with that. What about taking people back? Say you meet someone you like and you wanted to take them back would that be all right?*

P5 *Well, they said yes, they sat down with us and said anything that you've got on your mind, anything you want to talk about, they either take us to the side to another room or / I've asked them if it's alright, if I bring other people back to the home and they said yes.*

Likewise, at Para. 101 he states:

P5 *Yes, they said if I brought my girlfriend back or a friend I know, 'cause I've had loads of friends in my life girls and boys, you know, they say yes, it's your house you do what you want.*

However, he then went on to describe an occasion when he had received a visit from a young male with an interest in computer games. This person had previously visited him and no concerns had been raised. However, on one particular occasion, the person started discussing spirituality with participant five and then said he was tired and that he wished to close his eyes for a while. Participant five described the manner in which he handled the situation and decided that he wasn't going to invite the young man into his home again. He also told his carers about the incident. Rather than discussing with participant five the potential dangers of inviting people back to his home, how he might assess risk, and what he should do in the event that a situation occurred with which he was unhappy, the carers simply decided that the person in question could not visit participant five at home. Participant five also described the fact that if he was late returning home that staff would telephone others to find him or would go and look for him. He considered that such behaviours were in primarily in the interests of the carers:

P5, Paras. 56-57:

P5 *If I weren't back on time, um, they would start ringing round to see where I was, or look for me.*

Int. *Why do you think that is? Is it because they are worried about you or...*

P5 *It's part of general practice with them, to safeguard their backs, you know. As long as they know where I am or who I'm with then they're happy.*

3.2.1.b.ii. Giving home address and telephone number to new acquaintances and use of phone.

As with most of the participants who lived with family, participant five felt able to give people his phone number. However, similarly to those living with family, he recognised that there were potential dangers in doing so as shown in the following extract:

P5, Paras. 42-43;

Int. *Right. So you'd feel happy about giving them your phone number?*

P5 *Oh, yes, I would feel happy as long as they were honest abiding people and they wouldn't use the phone number for any other methods.*

3.2.1.b.iii. Concerns about vulnerability

As can be seen from the preceding sections, participant five's carers appeared to have some concerns about the vulnerability of those they supported, even if the concern may have been partly selfish. However, in addition to the concerns of his carers, participant five's parents were also concerned about his vulnerability. As with some of those living at home, this concern had a restrictive effect upon his life and had been internalised by him, as is demonstrated in the following extract.

P5, Paras. 21 – 27;

P5 *I have been asked to go out with (name of advocacy organisation) down to a club called F... which I haven't had the opportunity yet because of social, um, apprehensions have stopped me now, like my parents. They feel that I would be taken advantage of*

Int. *Right, so what's F, or where is it?*

P5 *It's a club, a night club in M (location).*

Int. *Right, but you said you think that your parents think you might be taken advantage of...*

P5 *Yes, I, I'm one of these people who can be, um, very vulnerable to, shall we say like ungood people, people who are / I used to go around and get in a lot of trouble once with gangs of groups of people which were unworthy to my family's eyes, you know. I've learned from that.*

3.2.1.c. Living alone

Only two of the participants lived on their own, namely participants four and nine. Although they lived on their own they did receive some support with daily living. In the case of participant four, this was formal assistance with housework and informal assistance from his family. For participant five, however, the support he received was limited to that which his parents, who lived approximately a mile from him, were able to offer.

Both participants who lived on their own felt able to take people home or receive visitors, though participant nine would only do so 'after getting to know them'. They would also consider giving people their telephone number and address. However, as with many of the other participants they appeared to recognise potential dangers in giving strangers these details as is demonstrated by the following extract from the interview with participant nine:

P9, Paras. 27 – 30;

Int. *So if you met somebody that you liked and you get chatting to them, um, would you give them contact details, I don't know, your phone number or address?*

P9 *If I met them a few times before hand, got to know them a bit better, talked to them, talked about me, asked about them, etc, then I give them contacts.*

Int. So if you meet somebody for the first time and think they're nice, I'd like to meet them again what do you do then, how do you arrange to meet them again?

P9 *I / if I do like them I ask them 1:1 would you like to meet again, are you interested, if not fair enough.*

Likewise in a manner similar to other participants, participant nine expressed some concerns about his vulnerability in certain situations. For example, he stated that he was wary about talking to unknown men in public houses.

3.2.1.d. Living arrangements and sense of place: Concluding remarks

The majority of participants may thus be seen to present a picture of restricted autonomy in relation to their living arrangements. They also suggest an unwillingness on the part of carers (whether formal or informal) to allow them to make the transition to adulthood or 'grow up'. Simply moving out of the parental home clearly does not necessarily result in an increase in an individual's independence. This finding is similar to that of other studies discussed previously such as Dorney (1999) March et al (1997) and Shepperdson (1995).

Moreover, for those participants living in family homes, one has the sense that they perceive themselves to be guests of their family rather than them having a sense of the home being theirs. This may account for the reason that so many of the participants wished to move from the family home. Despite such expressed preferences families are, in some cases, exerting pressure on their sons not to leave home, a finding similar to that of Flynn and Saleem (1986) in their study of the satisfaction of adults with a learning disability living with their parents.

3.2.2. Occupation and occupational aspirations:

This section of the findings and discussion is concerned with the occupation of the participants and their stated occupational aspirations.

3.2.2.a. Current occupation

Of the twelve participants, only one, participant six, had full time employment. This was in a local company that stripped pine and cleaned wheels. Although the work was dirty and dusty he stated that he enjoyed his employment. Three other participants had part time work. Participant four worked part time in the local Sainsbury's store, which he enjoyed, and participant two worked in a local McDonalds 'restaurant'. Participant three worked part time on a Friday laying tables and putting out biscuits. A further two participants had previously experienced job placements (participant two and participant eleven) but were not employed at the time of the study.

Two of the participants attended a local day centre. Whilst one of these, participant three, enjoyed attending four days a week, participant ten did not value it for himself as is demonstrated by the following interview extract:

P10, Paras. 15-16;

P10 *At the moment I go to the local day centre which give mum a break and it's like doing, I can't say small work, but it's like doing therapeutic work, and, um, I don't get paid for it.*

A further two participants attended a local woodwork unit for individuals with disabilities where they made garden furniture. Two other participants, (participants eight and nine) attended a part time Information Technology course at a local college of further education. Two participants (participant eleven & participant seven) had no planned regular occupation. Participant seven had previously attended the local day centre but left because he didn't enjoy the work.

3.2.2.b. *Occupational aspirations*

Of the participants who had some form of employment, only one, participant two wished to change his work. At the time of interviewing him he had worked in McDonalds for three years on a part time basis as a cleaner. Despite reporting the fact that he had been bullied by some of the staff he did not express a wish to leave. Rather, he wished to change the type of work undertaken:

P2, Para. 90:

P2 *I'm fed up I can't be allowed in the kitchen. Say I'm not doing the toilet anymore.*

Of those participants attending local day services, two wished to leave. The first, participant twelve, who already 'helped out' on his uncle's farm wished to work full time on a farm. The second, participant three, expressed the wish to work in catering.

3.2.2.c. *Occupation and occupational aspirations: Concluding remarks.*

The fact that few of the participants held what might be considered regular, paid employment is likely to have had a negative impact on their lives (Archer and Rhodes 1987). For as Gint (1991:14), states,

"...work provides both identity and material reward, and facilitates the reproduction of ritual and social obligations".

Although employment may not be the way to achieve self-realisation, nor a means of achieving sufficient wealth to compensate for its alienating consequences,

"...*the effects of unemployment are a clear indication that work is a central social institution and an essential part of most people's lives*" (Gint 1991:46).

Whilst the employment of men with a learning difficulty would not be a panacea for all the challenges they face, it may provide a number of advantages that would have a positive effect on aspects of their lives with which this study is concerned. For example, it may enable them to participate in and contribute to their community, it may provide a complex network of social relationships, it may engender self esteem, assist in overcoming prejudice and stigma and it may provide material rewards, with which they could purchase goods and services (Lane 1980; Pannell, Simons et al. 2000; Riddell, Baron et al. 2001). Additionally it may assist in defining their status and identity and facilitate increased independence (Beyer, Goodere et al. 1997).

3.2.3. Finances and sense of agency

This section of the findings and discussion is concerned with participants' finances and the impact these had on their sense of agency.

3.2.3.a. Income;

Given that only one participant was in full time employment (participant six), it is to be expected that he was the only person in receipt of a regular wage. For working thirty-five hours per week he received £145.62 (£4.16 pr. Hr.).

Those individuals working on a part time basis (participants two, three and four) received some payment for their work. Whilst they were unable to specify how much this was, they suggested that it was an appropriate rate.

The individuals attending the woodworking centre to make garden furniture (participants five and twelve) received a 'few pound' a week. Similarly participant three who attended the day centre received very little money, namely between £0.60 and £1.00 per week, whilst participant ten received no money for attending the day centre.

3.2.3.b. Control over finances:

The only participant having full control over his finances was participant six, who after paying his mother 'board and lodgings' kept the remainder of his money. Two of the individuals (participants nine and seven) had limited control over their money. For example, participant nine gave his mother his Disability Living Allowance, but appeared able to use his job seekers allowance as he saw fit:

P6, Para. 36:

P9 *I get job seekers allowance from the job centre and I'm also on disability living allowance which my mother takes care of ... But I mainly use my job seekers allowance money to go out and buy games, cds, magazines, etc.*

Most of the participants, however, had very little, if any control over their finances. For example, despite living in supported accommodation, participant five did not receive his benefits directly but was given £10 per week as 'pocket money' by his mother. Similarly participant eight was only given £3-4 on a Saturday by his mother.

3.2.3.c. Effect of limited income and control over finances

For all but participant seven, who felt he had enough money, limited income appears to have reduced participants' opportunities for community participation and meeting people who might potentially become friends. This was particularly the case for participant ten who, being a wheelchair user, was dependent on specialist transport;

P10, Para. 31:

Int. *Do you go to places like clubs and nightclubs?*

P10 *Yes I go to the pub, but as for going to a nightclub Paul, it's very rare 'cause I've got to rely on transport and pay and all my friends don't live in the same area.*

Even where participants had developed relationships, their limited finances meant they were not able to visit their friends or girlfriends as often as they might have wished as can be seen in the following two extracts:

P8, Paras. 85 -90

Int. *So, do you think you have enough money to go out and do the things you want to do?*

P8 *No, it's only on a Saturday when I'm with my, mmm, only on weekends away that I can actually say what I want to say to my friends an' all that.*

Int. *Right*

P8 *Because when I'm up here then I can umm, tell them what's happened in college and all that about my week that's gone by.*

Int. *So how much money, you don't have to answer this if you don't want to, but how much money do you have a week to spend on stuff? Do you have much or...*

P8 *No I only have a certain amount on a Saturday, three or four pound on a Saturday. But it's good I can come up here 'cause I can talk to my friends then.*

Int. *That's good, but it means you can't go out the rest of the week?*

P8 *No.*

<u>P11, Paras. 194 – 197</u>

Int. *So how often do you see your girlfriend?*

P11 *It used to be every day, then I had to have it reduced to 3 days a week then it went up to five days a week now it's gone down to once a week.*

Int. *So why is it once a week, is that because you're living in M (name of town) again?*

P11 *No, its, ah, mainly 'cause, well, one reason is money.*

Additionally they were unable to afford to carry out activities that many people would regard as 'ordinary' dating behaviour such as going to the pictures or out for a meal;

<u>P10, Para. 308</u>

Int. *So you used to kiss and things. Did you do things like go to the pictures together, what other sort of things did you do?*

P10 *No, cause of transport issues, and um, money costs an all.*

For another participant, (participant eleven) his limited finances and the fact that he owed his father money for catalogue goods, which his father had sold him, was perceived as preventing him from moving out of the family home:

<u>P11, Paras. 20 – 25</u>

Int. *So, um, would you like to move out of home?*

P11 *I'd like to but I can't at the moment because I've got debt up to my eyeballs. My father is agent for the catalogue, I bought loads, I've managed to pay loads off but I've shot myself back in the foot because I bought a brand new PC and it was over eight hundred quid.*

Int. *That's a lot of money.*

P11 *I want to get it paid. I've got eight hundred and eleven pound to pay out. It was eight hundred and ninety nine pound but it's gone down to eight hundred and eleven pound now at the moment.*

Int. *So do you have to pay that every week?*

P11 *Every two weeks, because I'm on jobseekers, see as well. Every time I have my jobseekers I give my money to my dad and he jots it down and it's coming off see. He reckons if I keep the payments up by the end of the year it should be down to about a hundred pound at least.*

Most of the participants, including participant six who was in full time employment, expressed a desire for more money. Participant five, whose mother gave him 'pocket money' gave his rationale for an increase as follows:

P5, Paras. 72-73

P5 *I get £10 a week*

Int. *Do you think that's enough or do you think you should get more or...*

P5 *Well, with age I've asked for a few things / with my age I've asked if I can have my pocket money upgraded, like a normal person would have enough money to cover them, you know, enough money to see them through for the week or forthcoming time.*

However, despite most participants expressing a desire for more money, only participant ten explicitly expressed a desire for greater control over his finances.

P10, Paras. 353 – 356

Int. *Ok. If you were training someone to work with you or with someone else what's the most important think you would say that they should do?*

P10 *Do you know Paul there is a direct payments for our care?*

Int. *() And you think that's important so people can choose their own carers?*

P10 *Yes*

3.2.3.d. Finances and sense of agency: Concluding remarks:

In summary, the majority of participants had a minimal income. In relation to this income most participants also had very limited control as to how such income was used. This reduced their autonomy and independence and meant that many were unable to afford to go out in order to meet existing or potential friends. It also reduced their opportunity to participate in community activities. It is sad to note that this finding is similar to that of Flynn (Flynn 1986) some eighteen years ago.

3.2.4. Community participation and inclusion:

This section is concerned with such things as the level of control participants have over their leisure time, the things they do, whether they need support in order to access leisure activities, the opportunities they have for meeting people and whether they value voluntary organisations that provide leisure opportunities for people with learning disabilities.

3.2.4.a. Control over leisure:

Few of the participants were fully able to exercise control over their leisure time. Both participants four and nine who lived alone were able to choose where they went, with whom and the time at which they returned to their homes. Participant five who lived in supported accommodation said that support staff were willing for him to go out alone as long as he told them where he was going and his likely time of return. However, despite living in supported accommodation, he made reference to the fact that he felt constrained from doing some activities by his parents as described in section 3.2.1.b.iii (concerns about vulnerability). Similarly, although participant four lived on his own and went out without support, he also went to local public houses with his parents during the week.

Of the remaining participants, three (participants six, seven and eleven) had a high level of control over their leisure and could go out with whoever they wished, to wherever they wished and held a key to their home in order that they could let themselves in. Two of these (participants seven and eleven) were, however, expected to let their parents know where they were going and the likely time of their return. However, this level of control was not as great as might at first appear to have been the case as a result of limited finances and public transport. For example, participant eleven related a, then, recent occasion on which he had gone to visit his girlfriend. Although he had managed to get half way home, he had missed the connecting bus service to his home town and could not afford to take a taxi. As his father had no transport, he presented himself at the police station and told them what had happened. They allowed him to sleep in the police station and he then caught the first bus home at 0800 the next morning.

Other participants had more limited control over their leisure time. For example, participant one was allowed to go out with a friend and to use public transport when out. However, he had to return home by 2230 hrs.

Two other participants, (participants eight and twelve) were allowed to attend their day time occupation and the Saturday daytime 'youth club' alone but did not appear to be allowed out on their own on other occasions. This can be seen in the following extracts from the interview with participant twelve who described how such restrictions caused him to feel.

<u>P12, Paras. 84 – 88;</u>

P12 *I go to the pub with my family and that's about it.*

Int. *Right*

P12 *That's it. I only go out with my family.*

Int. *Right. And how do you feel about that?*

P12 *Very upset, 'cause I want to go out and meet people and have a game of pool and things like that.*

<u>P12, Paras. 318 – 322;</u>

P12 *I'd like to go on my own and meet more people.*

Int. *Right. You were saying that your dad doesn't like you going out on your own.*

P12 *Um*

Int. *How do you feel about that?*

P12 *A bit peed off that I can't go out on my own with other lads.*

The remaining participants had very limited control over their leisure time. For example, other than attending his part-time employment, the Saturday 'youth club' and going out with his family, participant two only went out during the day with staff from the centre and was not able to go out at night.

P2, Paras. 81 – 86;

Int. *So you were saying you don't go out at night very often. Do you ever go out at night?*

P2 *No*

Int. *No? What if you wanted to, would that be ok?*

P2 *I like stay in*

Int. *You don't like going out?*

P2 *Not allowed to - just stay in all the time*

3.2.4.b. *Leisure activities undertaken by the participants.*

Given the varying level of control participants had over their leisure time, one would have expected that the activities undertaken by participants would also have been varied. However, other than participant eleven's interest in steam engines, an interest shared with both his father and his girlfriend's father, participant twelve's enjoyment of riding an automatic quad motorcycle on his uncle's farm and participant eight's interest in football, an interest shared with his father, there was little diversity in the activities participants undertook in their leisure time.

A number of them referred to visiting the local recreation centre to meet up with friends from one of the organisations they belonged to for people with a learning disability. When there, they would use the gym and the swimming pool and chat with one another. In addition to using the recreation centre, a number of the participants referred to visits to local public houses, attendance at 'inexpensive' discos and music events and attendance at one or more of the organisations they belonged to on a weekly basis. A further activity undertaken by five of the participants was the use of computers. For some like participant five, the main interest was in playing computer games. For others, they valued the learning environment available through computer software and the world-wide-web. Participant nine also described how computers could be used to meet people, though as the following quotation demonstrates he had not actually met any of his web contacts in a face to face situation:

P9, Paras. 97 – 106

Int. *So can you, 'cause I don't really use the internet a lot, can you tell me how that works?*

P9 *Um, I don't know if you've ever heard of, um, MSN messenger chat and Yahoo Chat?*

Int. *So you use the chat rooms and what, you just get chatting to people?*

P9 *Yes, basically. I don't know who they are, but I basically get to know them by, uh, asking them questions. If I know they're answering in a funny duddy way I say 'are you sure about this now'?*

Int. *So do you ever meet people that you've chatted to on the web?*

P9 *Have I ever met? No*

Int. *Right, Is that something that could happen, is it?*

P9 *I can't see it happening.*

Int. *Oh, I just wondered if you actually met up with them*

P9 *Oh, no.*

3.2.4.c. *Support to access leisure*

As with the level of control people had over their leisure time, the level of support participants received in accessing leisure activities varied. Although a number of participants used local amenities by themselves, most received support to access leisure further afield. Such support was provided by families, friends, paid carers from day services or voluntary staff from one of the organisations the participants belonged to.

Only participants one and five regularly went out alone, other than in their immediate locality. Even they received support from their family at times. However, it was not clear that the receipt of support was required or desired by the participants. For example, although participant five's attendance at steam rallies was facilitated by his being taken to the rallies, he demonstrates an ability to access locations such as the Capital city and a well known beach area alone when apparently frustrated at not being taken out:

P11, Paras. 7, 28 – 29;

P11 *I have a girlfriend named A who actually lives in P (name of town) and if it wasn't for her father I wouldn't be travelling to all these steam engine places, well I do go with my father, but mostly I go with her father as well...*

Int. *So at the moment if you want to go anywhere you have to go with A's dad or your dad has to take you. You can't get around any other way?*

P11 *Sometimes I do say to myself, forget them and jumps on the bus on my own. The places I go are to the M (seaside) or Cardiff, they're the places I go.*

One of the apparent difficulties faced by all participants in accessing leisure more independently appears to be the issue of transport as has been highlighted in this section and 3.2.3.c. That is to say, it has been noted that public transport in the areas in which the participants lived was expensive and not always available when desired. For the one participant who was a wheelchair user (participant ten), in addition to issues such as his bed time being determined by his home care service, access to transport appeared to be one of the main obstacles to his greater participation in community activities as is suggested by the following extracts from the interview with him.

P 10, Paras. 31, 70 – 71 & 307 – 308;

P10 *Yes I go to the pub, but as for going to a nightclub Paul, it's very rare 'cause I've got to rely on transport and pay and all my friends don't live in the same area.*

Int. *So you don't have enough money to go out and do things? You said you have a problem with transport getting out.*

P10 *yes*

Int. *If you did go out do you have to be back at a certain time?*

P10 *Yes, homecare, that's someone who gets me up and puts me to bed. That can be a bit of a drag.*

Int. *Did you do things like go to the pictures together, what other sort of things did you do?*

P10 *No, cause of transport issues, and um, money costs an all.*

3.2.4.d. General opportunities for meeting people

As can be seen from the above, the opportunities participants had for meeting people were generally limited to attending activities organised by others such as their families, paid carers and voluntary workers at the organisations they belonged to. Although some of the activities, such as attending steam rallies (participant eleven) and football matches (participant eight) were non-segregated activities in so far as they were open to the public rather than just persons with a learning disability, much of participants' leisure time was spent in organisations provided for people with a learning disability. Given the fact that many of the participants were taken to such places by family or were supported in attending by voluntary workers, it appeared unlikely that participants would have many opportunities to socialise outside of their peer group, families and support workers. Even when participants attended community facilities such as public houses and recreation centres it appeared that they generally refrained from talking to people other than their friends or people they knew:

P2, Para. 45 – 46;

Int. *So who do you go with, friends, mum and dad?*

P2 *Friends*

Int. *Ok. When you go there do you meet people you don't know? Do you meet new people or do you always just talk to the same people?*

P2 *Ah, the same people all the time, uh...*

Other participants such as participant five also suggested this was the case:

P5, Paras. 36 -37;

Int. *So do you meet many new people when you're out or do you mainly stick with the people you know?*

P5 *I mainly stick with the people/ um sometimes I stay with my friends and sometimes if I know someone I go and chat to them.*

However, this did not necessarily mean that participants were unsure of where or how they could meet new people as is made clear by participant six in the following extract:

P6, Paras. 67 -72;

Int. *So all these places you go like the pub and the Reck and here do you very often meet new people or is it usually the same people?*

P6 *The same people*

Int. *So what about / do you go any places you meet new people?*

P6 *That would be pubs and clubs and things like that.*

Int. *It could be.*

P6 *It could be out at the bus stop, talking.*

3.2.4.e. The perceived value of voluntary organisations

It generally appeared that if participants had not been members of one of the organisations they belonged to, their leisure activities would have been even more limited than was the case. Five of the participants commented on the value they perceived membership of one or more of the organisations brought. Whilst one of the participants (participant twelve) was not sure what he thought of the organisation he belonged to, having only joined four weeks previously, the other four participants who commented on this issue perceived the organisations to be beneficial.

One perceived benefit was that participants felt comfortable as a member of the organisations and less likely to be ridiculed as a result of being learning-disabled. For example, participant seven described a situation where he was ridiculed by some girls in a pub and then stated that this was one of the reasons he did not generally go out alone, despite his parents being willing for him to do so. Even if he did go out alone, he no longer spoke to people he didn't know:

<u>P 7, Paras. 112 – 115</u>

Int. *So, you come to places like this. Do you come to places like this because you feel happier, because you don't feel people are going to be nasty, or...*

P7 *Yeah, I feel happier, yeah.*

Int. *So, going to other places, the girls, have made you feel... I don't know what have they made you feel, scared of talking to other people or...*

P7 *Yeah, a bit.*

Other participants described different advantages of membership of the organisation. For example, belonging to an organisation was seen as 'life changing' for participant ten as the following extract demonstrates:

<u>P10, Paras. 18 – 21;</u>

Int. *So the times you get to meet people...?*

P10 *E (organisation) has brought a big change in my life*

Int. *Right. In what way, can you tell me how?*

P10 *I know I shouldn't say this 'cause it's rude, I owe a lot of it to M, 'cause he has a part in everyone's life but especially mine.*

Whilst at this point in the interview he appeared unable to give explicit reasons for his positive feelings towards the organisation, he later referred to feeling valued as a 'member of a squad' and the fact that the organisation was one place where he was treated as equal by the voluntary workers.

Another participant expressed the more positive view that belonging to such an organisation actually promoted community inclusion and participation:
P6, Paras. 140 -146;

Int. *Ok. So is there anything else you want to tell me about how often you meet people or how easy it is for you to make friends?*

P6 E (organisation) is good, 'cause it gets people out in the community and building relationships. It's good to get the public to know more about E (organisation) and what it does because it's such a good project to the community especially people with learning disabilities, they get people out doing things like going to clubs and getting into relationships and things.

Int. *If you didn't have E (organisation) do you think you'd do that sort of thing?*

P6 *No, I would do some things but with support then.*

Int. *So E has been good for you then?*

P6 *Yes, it's helped me out quite a bit.*

Int. *Good.*

P6 *It gets me out and about instead of being bored watching the TV, 'cause that's what I would do or my jigsaws.*

3.2.4.f. Community participation and inclusion: Concluding remarks

In the past, concern was expressed about the restriction placed on the lives of people with learning disabilities who resided in large institutions (see section 1.4.5.). As a result of this, there was a move, albeit protracted, to close such institutions and place men and women with learning difficulties in smaller community based settings. Despite the fact that all of the participants in this study were living in the community and that many of the participants had never experienced living in 'institutional' settings one is presented with the overall picture that many of the participants led restricted lives. This finding is similar to that of Simons et al (1989) who reported some fifteen years ago that although people preferred living in the community to a large institution, their social lives were still relatively restricted. It also supports McCarthy's (1999) finding that in relation to factors such as control and sexual pleasure the overall situation was only minimally better for women living in the community than those living in institutions.

Additionally, it appeared that most of the people referred to by the participants as 'friends' were either relatives or other individuals with a learning disability. Few people had friends outside of such persons. This appears to be a common finding in a number of studies (Ehlers-Flint 2002). Likewise, most of the interests, activities or hobbies referred to by the men were either based at home, undertaken with the family or as a member of a group of people with a learning difficulty. These findings are similar to those of Flynn and Saleem (1986) in their study of the satisfaction of adults with a learning difficulty living in their parents' home.

Such a restricted lifestyle might be seen by some as a direct result of the individual's learning disability. However, if one takes a social model of disability approach rather than a bio-medical or functional approach based on the individual's pathology (Rioux 1997), it becomes clear that such restrictions are primarily due to a lack of opportunities and resources available to the men. This finding is thus similar to that of Dorney (1999).

3.2.5. Attitudes to and experience of platonic relationships.

Having previously discussed the opportunities participants had for developing relationships, this theme considers the attitudes participants held in relation to platonic relationships and any experiences of such relationships they felt it important to discuss.

Only five of the participants discussed platonic relationships. None of them discussed friendships with non-learning disabled individuals other than participant three who described two of the voluntary workers at the group he attended as friends. The remaining four who discussed friends did not include support workers, whether paid or voluntary, as friends.

Two of the participants had maintained friendships over a number of years with people they had met in school. In both cases, these friendships appeared to be quite strong. For example, participant one described how he and his friend wished to share accommodation together and participant six described how he sometimes stayed overnight at his friend's home and the fact that he either saw his friend almost daily or telephoned him.

Participant seven also had friends with whom he sometimes stayed. He also described how he went with his friends to local public houses. Although his friendships did not appear as strong as participant one's or participant two's friendships, participant seven did express the view that he would like to go on holiday with his friends if he could save sufficient money.

Whilst the participants predominantly described their platonic relationships in terms of the time they had known their friends and the types of activities they undertook with them, one of the participants (participant five) explicitly discussed the importance of trust within relationships, stating that:

P5, Paras. 395-397;

P5 *The main thing in a relationship is trust.*

Int. *Ok*

P5 *If you've got trust you know where you stand with people. That's it. I've always thought that, being, uh, to have someone's trust is the main thing to have in life is trust.*

Although not explicitly mentioned, trust and the opportunity to share confidences and offer one another support also appeared to be an important aspect of friendship for participant eleven:

P11, Paras. 47 - 50

P11 *When I first met him, well his girlfriend M introduced me to him and of course I wasn't,... I clammed all up, I couldn't talk to him for a bit, for ages. As soon as he started talking to me we was alright then, but...*

Int. *So how did you meet H, through your girlfriend?*

P11 *Through his girlfriend, well, it was his girlfriend at the time, but whether they're boyfriend, girlfriend now I'm not sure, cause H is always on to me, 'she's finished with me, she's finished with me'. I talk to her and fair play she goes back to him and then next minute then they argue again and what I say to him, I say 'H, right I've had a word with her and she'll go back with you this time but she'll not go back with you again'. They're still together.*

Similarly, participant eight stated that:

P8, Paras. 86 – 88;

P8 *It's only on a Saturday when I'm with my, mmm, only on weekends away that I can actually say what I want to say to my friends an' all that.*

Int. *Right*

P8 *Because when I'm up here then I can, umm, tell them what's happened in college and all that about my week that's gone by.*

3.2.5.a. Difficulties in developing and maintaining friendships:

Whilst some of the participants saw or telephoned each other almost daily, this was not the situation for most participants. Rather, for a number of participants, the opportunities they had for developing and maintaining friendships were limited by various factors. Some of these have already been referred to such as the accessibility or otherwise of public transport and the lack of sufficient money to meet with friends. A further factor related to the accommodation the participant resided in. For example, although participant three described himself as being able to take friends home, he also referred to the fact that until shortly prior to the interview he had shared a bedroom with his brother. This appeared to restrict his opportunities for entertaining friends at home:

P3, Paras. 128 -131;

Int. *If you wanted to take friends home and you wanted to be on your own with them and you didn't want any interruptions would that be ok?*

P3 *Yeah, well my brother.*

Int. *Did you share a bedroom with your brother or?*

P3 *Yeah, same bedroom. I got a new bed now.*

Whilst this was not explicitly an issue for other participants in relation to platonic relationships it will later be seen that privacy was an important issue in relation to intimate and personal relationships.

3.2.5.b. Attitudes to and experience of platonic relationships: Concluding remarks

That participants had few friends generally and in particular few friends without a learning disability should not be surprising to the reader given the lack of opportunities the participants had to engage with their local communities, whether this was due to lack of finances, lack of transport, lack of appropriate support or a general lack of autonomy in their lives. Such limits clearly reduce participants' opportunities for developing platonic relationships with non-learning disabled individuals.

They did, however, have opportunities to develop friendships with other individuals with a learning disability either at 'work' or socially. Whilst such friendships may not be considered 'ideal' by those working towards policy frameworks based on social role valorisation or the 'five accomplishments', they were clearly of value to those participants who discussed platonic relationships. They valued such relationships in terms of them having someone to talk to, someone to trust and someone they could both offer and receive support from. This finding is not surprising given that all human beings are generally viewed as interdependent and affiliative in nature, both needing one another and having a desire to feel needed (Gross 1996; Buunk 2001; Llewellyn and McConnell 2002). Moreover, it is generally recognised that relationships and social support act as a cushion against stressors that may be encountered in the course of one's life (Callaghan and Morrisey 1993; Llewellyn and McConnell 2002).

3.2.6. Sense of self:

This theme encompasses a number of sub-themes relating to such things as self-perception, body image and masculinity.

3.2.6.a. Satisfaction with body image:

Whilst the extent to which one is conscious of one's bodies and body image varies over time and place, it can have considerable impact on ones health, one's relationships with others (Nettleton and Watson 1998; Jones 2001) and on one's 'sex life'(Hoyt and Kogan 2001). This section seeks to outline the experience the participants had of their bodies.

Of the twelve participants, only one (participant one) stated that he was happy with the way he looked. Another, (participant nine) had mixed views about his body noting that whilst at times he would like a 'six pack' at other times he felt fine about his body. Interestingly in relation to how he perceived his attractiveness to women, he didn't appear so concerned about his body image as with his personality:

P9, Para. 58

P9 *Sometimes I feel like I want to well, I want, sometimes I want a six pack, sometimes I feel I look fine, but when I'm, when I'm, when I'm drunk or what ever, I don't care, I don't give two monkeys. But when it comes to women or girls I do feel a bit down, because I don't worry about the way I look, I worry because is she going to like me and things like that.*

Int. *So what sort of things do you think they like?*

P9 *Mostly, some of them , I'm not sure how many of them like personalities and not what we look like, not sure how many of them work on that basis, I'm not sure, but I think most of them that I have met, they are more interested in, um, what's up here, not what's down there.*

The extent to which the remainder of the participants were satisfied with their body image varied considerably.

Only two of the participants had disorders that affected their physical appearance and / or abilities, namely participant ten who had Cerebral Palsy and participant six who had Perthes Disease. Participant six had accepted the fact that he will need surgery and may have to be immobilised in plaster for a considerable period of time, although he didn't enjoy having blood tests or injections:

P6, Paras. 153 – 155;

Int. *You said you have Perthes disease and that was going to cause you problems in the future. Does that make you feel sad or do you feel ok?*

P6 *I feel ok 'cause I know I've had it since I was a baby.*

Int. *Right.*

P6 *But I don't like the needles. I have to have tests and they have to put needles in to stop me lifting so much, but I'm ok with my hip I take it / If it plays up I have a tablet and then I don't take a tablet when it don't play up I only take them if I need to.*

Participant ten, on the other hand, expressed the view that he didn't like anything about his body. In particular he implied that he would like to be able to walk and pick things up using an ordinary grip:

P 10, Paras.

Int. *Are there any things / you know you see men going off to the gym to make themselves more attractive, are you happy with your body?*

P10 *No, I'm not happy with my legs 'cause I desperately want to get out of this (indicates wheelchair) and walk.*

Int. *So, if you could you would change your legs.*

P10 *Yes.*

Int. *Is there anything you like about your body, is there anything you think that's a really nice part of me?*

P10 *Well ().*

Int. *For example you might think you've got a really nice smile.*

P10 *The other thing I dislike about my body is that I pick up a cup with my forehands, I have to pick up a cup like that, (demonstrates that he picks up cups with the back of his hands) like my friends are supportive in the village but sometimes they will pick up a cup like me and it gets me down.*

Int. *So you'd like to change your legs and your hands. Is their anything you do like about your body? I don't know, do you like your face, is there anything you think, 'that's nice, I want that to stay like it is'?*

P10 *Um, no.*

Three other participants (participants seven, nine and eleven) wished to change the fact that they wore spectacles. Only one (participant nine) gave a reason for desiring this change, namely that he felt embarrassed and stupid wearing them:

P 9, Paras. 69 – 70

Int. *So you wear glasses sometimes?*

P9 *Sometimes. Sometimes I'm, well a bit embarrassed when I wear them 'cause people are so used to looking at me without glasses and like, um, one time when I went for an eye test a month or two back now I had glasses and my mother looked at me and she had a great smirk on her face, a great smirk on her face, I felt, I didn't feel embarrassed, I just felt like an idiot wearing them.*

All three were aware that there were alternatives to spectacles such as contact lenses and laser treatment and participants seven and eleven expressed the view that if they were able to afford laser treatment they would do so. As can be seen by the quotation from the interview with participant seven, he had obviously given consideration to the matter and weighed up some of the pros and cons:

P7, Paras. 127 -131

P7 *I would have it, if I had the money I would. I been talking to my mother about that.*

Int. *Do you know how much it is?*

P7 *Different prices on adverts I've seen, £400 each eye and stuff like that and £500, I've seen.*

Int. *That's a lot of money isn't it? But if you had the money...*

P7 *Yes, I would do. I wouldn't loose my glasses and stuff and break them then.*

A number of the participants (participants two, three, five and twelve) expressed a desire to have a different body shape that was more in line with that of the 'ideal' male. For example, participant two discussed enlarging his musculature around his shoulders, back and stomach. Likewise, participant five wished to improve his physique so he looked more like Jean Claude Van-Dam, a film actor.

Even those who expressed the view that they thought they were attractive and generally liked their bodies expressed the view that they wished to change something about their bodies. For example, participants three and eleven wished to be slimmer or more muscled, whilst participant four, although he was unwilling to discuss why this was the case, stated that he didn't like his 'private parts'.

3.2.6.b. Attempts to change body image:

Given the high number of participants who expressed dissatisfaction with their body image, one might have expected a similar number to proactively seek to change this, but this was not the case. However, given that the body is both a biological and sociological phenomenon and that one's body image is mediated by cultural and social context (Nettleton and Watson 1998) perhaps this is not so strange. For example, whilst a man with a learning disability may perceive his body image as less than 'ideal', he may have been socialised into acceptance of this and may not feel able to bring about any desired change.

Half of the participants stated that they behaved in ways in which they hoped to alter their body image. Behaviours were varied and included dieting (participant three), doing sit-ups (participant nine), swimming (participant five) picking up bales on his uncles farm (participant twelve), participating in athletics events (participant three) and going to the gym up to four times per week (participant two).

For some, the wish to change their body shape was ascribed to health issues. For example, participant six was dieting in order to reduce the immediacy of an operation as a result of his having Perthe's Disease. For others, the desire appeared to be more related to modern socio-cultural perceptions of the 'ideal' male body with its emphasis on appearance and image (Twigg 2002) and with peer pressure as is demonstrated by the following extract from the interview with participant five:

P5, Para. 121

P5 *Well I feel about my body, I feel about my body, I feel I'd like to improve my body structure, more muscles, um, my physique. I'd like to have a better physique than what I got now 'cause when you go out with the boys or my friends they are butch and have got muscles, not muscle bound but they turn round and say D you're the only puny one in (unclear).*

3.2.6.c. Perception of self in comparison to other men.

Participants described themselves both as how they saw themselves as individuals and in relation to how they perceived other men.

Only four of the participants (participants seven, nine, eleven and twelve) described themselves in terms of their similarities to other men. For example, when asked if he saw himself as the same as any other man or whether he saw himself differently, participant eleven stated:

P11, Para. 77

P11 *I see myself as the same really*

Similarly, participant twelve stated:

P12, Para 136;

R12 *The same as everyone else.*

Participant seven, however, whilst perceiving himself as looking the same as other men recognised cognitive difference as being the reason that he was teased:

P7, Paras. 107 – 109;

P7 *I look like other men*

Int. *Ok. So why do you think that the girls were taking the Mick out of you?*

P7 *'Cause I'm not as bright as other ones.*

Likewise, participant eleven had accepted the 'professional view' that he was different:

P11, Para. 203;

P11 *Eventually M Comp (name of comprehensive school) wanted me to go for an assessment and they come to the conclusion that I've got the mind of a six year old. Which I know most people around here don't believe me. I reckon its true, like, cause a 20 year old man don't go round playing with little toy cars or going out with kids playing cars with them. Obviously it's got to be true, 'cause otherwise it wouldn't be happening. I've got a massive bag of cars and when I was about 11 my father told me I was too old for them and to get rid of them but I wouldn't. Now I want to get rid of them he won't let me. Cause, I was thinking about it last night and I thought I'd be lost without all my cars. Ah. ()*

The remaining participants described themselves in terms of their difference to other men. For example, participant eight focused on the fact that he required support at times:

P8, Para 116 – 118:

P8 *I'm different.*

Int. *Ok, so what is it that you think is different?*

P8 *My um disability and all that, the things I can't do. I've got to have people with me to support me.*

Participant five, on the other hand, had assimilated a view that there is a core biological difference between those with and without learning disabilities:

P5, Para. 271:

P5 *Well, yeah, I think all people with learning difficulties, male or female, we are, our genes are the same, we are genetically different to a normal person.*

He also suggested difference in the form of the responsibilities non-learning disabled men may have:

P5, Para.117:

P5 *I see a normal structured man would have that, these responsibilities in life, like going to, getting up in the morning, seeing to his family, seeing to his wife, you know making sure his wife is ok and things like that and having that normal circle of life within the family.*

Such findings are similar to the belief that men with a physical disability challenge the generally held notions of maleness. That is to say that people with physical disabilities are seen as dependent, childlike and helpless (Waxman 1994). Whilst most of the men in this study did not have a physical disability, they were seen in a similar light and clearly experienced a lack of control over their many aspects of their lives.

3.2.6.c.i. Perception of self as Transgendered or homosexual.

One participant, (participant five), expressed the view that he would like a sex change. However, he felt that this would not be possible:

P5, Para. 125 -129;

P5 *I've always wanted a sex change.*

Int. *Right.*

P5 *I've always thought, being a man, I'd like to experience the female side of life.*

Int. *Right.*

P5 *But that will never happen in a million years, so I've got to live the way I am.*

Int. *Why do you say that will never happen in a million years?*

P5 *You've got to have money for these type of things and you've got to, you know, know the right people and the right connections and things like that.*

He also stated that he had thought he might be homosexual and that he would like to be able to experiment sexually. However, he did not feel this was possible due to other's negative attitudes about homosexuality:

P5, Paras. 139 – 141

P5 *No, if I went that way, beside, it's everybody's choice, if they want to be gay that's up to them, um if wanted to I think I would lose a lot of friends and my family bondage and that's what frightens me about that.*

Int. *Ok. Is that because you think that they don't think it's right, or...*

P5 *They think it's odd, it's not right, you know, it shouldn't be in society...*

Possibly as a result of feeling that neither of the above were possible, he instead appeared to accept the socio-cultural norm with regard to the ideal male body and expressed a desire to change his body image:

P5, Paras. 183 - 185

P5 *If I had a chance to change my whole appearance and my body I would.*

Int. *So () how would you like to look?*

P5 *Um, more, more, butcher, and more, um, attractive to the opposite sex.*

3.2.6.c.ii. Perceived ability to satisfy others sexually:

Only two participants made any reference to this concept, participants five and ten. Participant ten, despite saying that he got ' a hard-on' felt embarrassed by the fact that he had pressure sores and perceived himself as being unable to satisfy anyone sexually.

P10, Para. 179

P10 *I know I shouldn't say it because I feel embarrassed telling you is I have a load of sores down there (points to buttocks) and I couldn't have sex anyway.*

Participant five, however, despite his feelings that he would like a sex change and be able to experiment sexually expressed the view that he was able to satisfy others sexually:

P5, Paras. 349 – 351;

P5 *I've slept with loads of girls and had full contact sex and really enjoyed it, and the other person has really enjoyed it as well.*

Int. *Good.*

P5 *They call me the stallion, all the girls do.*

3.2.6.d. Sense of self: Concluding remarks

Overall, one is presented with a picture of the participants having low self-esteem. This finding is not dissimilar to the findings of studies of women with learning disabilities. For example, low self-esteem and self-worth were seen to be common amongst the women in the studies undertaken by Dorney (1999) and McCarthy (1998).

The majority of men in this study expressed some dissatisfaction with their body image, a similar finding to that of McCarthy in relation to the women she studied

(McCarthy 1998). Given that research has demonstrated a correlation between self esteem and body image (Polce-Lynch, Myers et al. 2001) the findings in relation to the participants' body image are important. Although it is generally acknowledged that women have become less satisfied with their physical appearance over the last thirty years (Hoyt and Kogan 2001) this does not appear to be the case in relation to men. However, studies do demonstrate that over the last fifteen years, men have become more concerned about their bodies and conforming to an 'idealised' muscular 'v' shaped body (Hoyt and Kogan 2001; Ricciardelli and McCabe 2001). The ideal man is young, lean and has good upper body strength, with a broad chest, 'six pack' abdominal muscles and bulging biceps. Additionally he has attractive facial characteristics (Jones 2001). This muscular 'ideal' is generally considered to be associated with socio-cultural views of the male sex-role and of masculinity. That is to say the ideal male should be strong, powerful, independent and efficient (Ricciardelli and McCabe 2001).

Recent studies also suggest that men are no longer solely concerned with their upper bodies but are focusing on their overall appearance (Hoyt and Kogan 2001). One study of particular interest is that undertaken by Ricciardelli and McCabe (2001), in that they found that adolescent boys with low self-esteem were more likely to be affected by socio-cultural pressures to change their body image than those with higher self-esteem. This finding may help explain the high incidence of expressed body dissatisfaction by the participants in this study in that most of the men in the study appeared to have low self-esteem. Unfortunately, however, Ricciardelli and McCabe (2001) do not answer the question whether low self-esteem precedes negative body image or vice versa.

Whereas other studies have found that people with learning disabilities may see themselves in terms of their similarities with non-learning disabled adults (Atkinson and Walmsley 1999; Watson 2002), few of the participants in this study expressed such a view. Rather, most participants in this study described themselves in terms of their difference to other men. Why this is so is unclear, however it may be due to the fact that all the participants in this study had 'come out' as having a learning disability in so far as they were active members of self-advocacy type organisations and a number spent time 'educating' others such as school children and the police as to 'what it means' to have a learning difficulty.

3.2.7. Understanding others through being male:

In addition to discussing how they perceived themselves as men, some participants discussed how they perceived women, homosexuals and people with physical disabilities.

3.2.7.a. Attitudes to women generally

When asked whether they thought men and women were the same or different in relation to equality, most of the participants initially expressed the view that they thought that women were equal to men. It appeared that some of the participants had received some form of anti-discrimination training as can be seen from the following extract of the interview with participant five:

P5, Paras. 276 – 277;

Int. *Ok. Thinking about men and women and relationships, do you think that men are better than women or that they are equal or women are better than men?*

P5 *That's being sexist that is. I can't say nothing about that because we're all equal.*

However, having commenced by stating that men and women are equal, a number then expressed the view that there were some things that men were better at than women and vice versa. For example, participants five and twelve felt that men were better drivers as shown in the following extract:

P12, Paras. 269 – 276;

Int. *Ok. So do you think that there are some things that women are better at than men?*

P12 *Women can't drive*

Int. *Women can't drive?*

P12 *No. Like my sister she can't drive. She just aims it.*

Likewise, participants seven and nine thought that some jobs were suited more to one sex or the other as can be seen in the following extract from the interview with participant nine:

P9, Paras. 214 – 220

P9 *When it comes to, uh, jobs, um, 'cause the job world is more centred around the males, I've got a feeling that males can do a better job because it's more suited to them.*

Int. *Right.*

P9 *Compared to a woman. Like it's normal now for a woman to work in a factory, for a woman to work as a shop manager, that's normal, that's normal to me. But when it comes to things like iron, um, engineer, making iron, metals, something like that, I don't think it's suitable for women.*

Int. *Ok.*

P9 *But if it's a shop manager, like I said...*

Int. *So some things, you think it is better if certain sexes do them?*

P9 *Yes.*

This apparent belief that men are better at some things than women appears to have been influenced by the participants' families as is demonstrated in the following extract from participant six:

<u>P6, Paras. 351 – 355;</u>

Int. *Ok, so...*

P6 *'Cause women can spend and spend and spend and spend until they drop. (laughs).*

Int. *So who told you that then?*

P6 *I know, it's like that for any kind of lady in it. It's their main thing. You give them money and they go out shopping and there's no money left when they get back. It's all expensive stuff they buy.*

Int. *Does your dad say that about your mum? Does he say she spends all his money?*

P6 *Yes.*

Interestingly, although most of the participants provide examples of how men are better than women at some things or vice versa, when they discuss their current relationships they emphasise the dual responsibilities of partners and suggest that they would share tasks according to each other's strengths and weaknesses:

<u>P2, Paras. 293 – 303;</u>

Int. *Are there some things that you think your missis should do or will you both do the same things?*

P2 *My missis she likes doing shopping, she'll check the money and things*

Int. *She's good with money is she?*

P2 *She can count money. When we buy things at the till she checks the money*

Int. *Good. So who will do the cooking when you are living together?*

P2 *(points to self)*

Int. *You're a good cook?*

P2 *I always cook see.*

Int *What about cleaning, are you going to do it all, or are you going to share it?*

P2 *We'll share it ok. My missis wants to sit down, I'll make her a cup of coffee.*

Such a division of labour was also suggested by those who were not living with a girlfriend or boyfriend at the time of the study but wished to:

<u>P5, Paras. 283 – 287</u>

P5 *At the moment I'm living with my friend (male) and we've got a rota there now, 'cause I asked for a rota. In the beginning we were fighting over the cleaning and things like that. If I had a female friend we'd have none of that. It would be down to each other who does what, you know you do the living room one day, I'll do the bathroom the next, I think everyone is up to their own duties, aren't they?*

Int. *So you'd split it fairly?*

P5 *We'd share it.*

Int. *What about things like cooking, are you good at that?*

P5 *I'm pretty good cook, you know. Give me a wok or give me a kitchen I bring up something. Something into nothing, fit for a king, you know. I'm pretty good on the cooker and in the kitchen.*

3.2.7.b. Attitudes to women with a learning disability

Some participants discussed their attitudes towards women with a learning disability. Only two (participants six and eleven) saw women with learning disabilities as being the same as women without a learning disability. The following extract from the interview with participant six suggests that he based this opinion on a human rights approach:

P6 Paras. 312 -316

Int. *Right, thinking about relationships, do you think that women with learning disabilities are the same as women without learning disabilities?*

P6 *I think it's the same without learning disabilities, cause, uh, disability people have the right to do whatever they want to do, because, uh, it's just like us public like they got a right to do it if they want to. It should be both ways instead of disability can't. Its, uh / I think that disability have the right to do what they want.*

Other participants described ways in which they believed women with learning disabilities were different to women without learning disabilities. For example, although he was going out with a woman with a learning disability participant five questioned whether a woman with a learning disability had the same feelings as a 'normal woman'. A further example is that given by participant nine, who expressed the view that in his experience women with learning disabilities were not as knowledgeable about socio-sexual matters as women without a learning disability.

Despite a number of the men expressing a view that women with learning disabilities were different to women without learning disabilities, many did not express a preference when asked whether they would prefer to go out with a woman with or without a learning disability. Of those who did express a preference, two expressed the view that they would prefer to go out with a female without a learning disability. Whilst participant twelve did not give a reason for this choice, he did express the view that in reality he wouldn't have such a choice. However, participant ten suggested that going out with a woman without a learning disability would improve other's perceptions of him:

P10, Para. 271;

Int. *Do you think that women with learning disabilities are the same as women without learning disabilities, or...*

P10 *No*

Int. *What's different about them?*

P10 *I've got to be careful how I say this.*

Int. *Say it however you want.*

P10 *...I would say, like there's no / if you go out with someone without a learning disability then you're normal.*

3.2.7.c. *Attitudes to relationships with women with a physical disability.*

Only two participants referred to how they perceived women with a physical disability. The first, (participant nine,) expressed the view that he would be willing to go out with a woman with a physical disability:

P9, Para. 82

P9 *It wouldn't matter if they had, if they were deformed or had some learning disability, it wouldn't matter.*

Participant ten, himself a wheelchair user, said that he would prefer to go out with someone who could walk:

P10, Paras. 114 – 119;

Int. *Yes. So you'd prefer to go out with someone...*

R10 *Normal*

Int. *Someone without a learning disabilities or physical disabilities?*

P10 *I don't mind learning disabilities, I mean someone in a chair.*

Int. *So you are saying you would like to go out with someone who is mobile, who could walk?*

P10 *Yes.*

Two suggested reasons are provided for this choice. Firstly that he saw physically disabled women as 'abnormal' and secondly because going out with someone with a physical disability would result in him taking on responsibilities he was unwilling to accept.

P10, Para.113;

P10 *I've always said in the past, and I'm not criticising anybody, I wouldn't go with anyone with special needs cause, cause I see myself as normal and it's taking, when () excuse me, when you go with someone with special needs you take on her responsibilities yourself.*

3.2.7.d. *Attitudes towards lesbians and gay men:*

3.2.7.d.i. Attitudes to Lesbians;

Participants were asked what they thought about same sex relationships. In relation to their attitudes to lesbians, four participants (participants one, four, five and six) thought that this was wrong. Some of the feelings expressed were quite strong:

P4, Para.133;

P4 *That's wrong. She should have sex with the man's body.*

Likewise, participant five, although he had expressed the view that he would like to experiment sexually, stated:

P5, Paras. 241;

P5 *I think it's disgusting having two women performing a sexual act with each other, knowing that they are both females.*

Three participants appeared to have mixed views on the matter. For example, participant ten commenced by stating that it was wrong but then appeared to change his mind to a more permissive though not necessarily more positive view:

P10, Paras. 202 - 209

Int. *Right. So do you think its ok for two women to have sex?*

P10 *No, definitely not*

Int. *Ok. What about...*

P10 *If they love each other yes, but if they don't ()*

Int. *So it's about whether they love each other is it?*

P10 *No, I'm not saying that, if one is straight and the other is bent and the one tries to turn the other one that's wrong.*

Int. *Ok. But if they are both, as you put it, 'bent', that's ok is it?*

P10 *Yeah.*

Participant eleven on the other hand, whilst he appeared to accept the idea of lesbians, referred to them in such a way that one was left wondering whether his 'real view' was that they were somehow 'subhuman':

P11, Paras. 134 – 137;

Int. *Is there any other sexual activity you think is wrong?*

P11 *No*

Int. *What about women having a sexual relationship with other women?*

P11 *Not really*

Int. *That's ok is it?*

P11 *Its, its just like human beings really*

The remaining two participants who commented on this issue, participants nine and twelve simply stated that they were not sure whether it was acceptable.

3.2.7.d.ii. Attitudes to gay men;

Surprisingly, the participants were slightly less negative about gay men. Only three (participants six, nine and twelve) thought that this was wrong. Participant nine who had been unsure of his views on lesbians, was, however, clear about his views on gay relationships:

P9, Para 144:

P9 *I find that offensive two men together, when I see two men together, um, being, () you know when two people are together and they, uh, you know, I get offended by that.*

Participant six who also thought it was wrong to be lesbian gave an explanation for his view which appeared to be based on societal intolerance directed towards same sex partners:

P6, Paras. 270 – 277;

Int. *There's lots of different people can have sex, aren't there, men and women can have sex...*

P6 *And men and men, an' that's wrong 'cause it's gay in it?*

Int. *What about women and women?*

P6 *That would be gay as well.*

Int. *Is that wrong or right?*

P6 *That's wrong.*

Int. *Can you tell me why it's wrong?*

P6 *Cause people will look at you weird and things like that.*

Participant ten who had been unclear about his views on lesbians was not openly hostile to gay men, but having described an experience he had in a youth club stated:

P10, Para 253;

P10 *And in the end I was, sorry to interrupt, I was getting called 'gay', 'Where's your boyfriend A?' I got really upset...*

This may be interpreted as him being homophobic in that he had a fear of, or aversion to being perceived and / or labelled as being homosexual. Whether this is the case is not fully clear. However, it does demonstrate the way in which homophobia may be used to 'police' the boundaries of 'traditional' masculinity (Seidler 1997) and the negative impact that homophobia may have on people who perceive themselves as heterosexual let alone those who may actually be homosexual or bisexual.

Only one participant who was accepting of gay relationships gave any rationale for this. Interestingly, he didn't apply the same rationale when expressing his view towards lesbians as outlined above. Participant five appeared to accept homosexuality for two reasons. Firstly he had personal knowledge of people in such relationships and secondly because he felt discrimination was not warranted in today's society.

P5, Para 242 -243;

Int. *Ok. What about two men, is that ok?*

P5 *I think if two men were compatible and they knew each other well, I'm all go for gay relationships and gay sex and I think it's a free world it's how people want to be. You can't say it's wrong for two men, 'cause, you find that sort of thing in college. There were two boys in school when I were there and they were a bonding relationship and they were walking around arm in arm and I thought, you know, nothing wrong with it. Years ago people used to demoralise it and they did think it shouldn't be allowed. But now it's past the millennium, turn of the century and people live their lives the way they want to.*

3.2.7.e. Understanding others through being male: Concluding remarks

It appears to be the case that despite initially expressing the view that men and women are equal many of the men in this study did not in actuality believe this. Rather, they expressed beliefs that there were differences between the sexes in relation to their abilities, aptitudes and the appropriateness of labour division. This suggests that equal opportunities legislation and the work of feminists and pro-feminists has not had a large impact on the beliefs of the participants. However, such a variety of views may be found amongst men without a learning disability and it is to be expected that the participants would have assimilated the views of their parents and the societies in which they live.

Having noted such attitudes, the fact that many expressed a desire or willingness to share tasks in accordance with the perceived strengths of themselves or their partners suggests that attitudes need not necessarily be predictive of behaviour, a finding similar to that in mainstream psychology (Bohner and Wanke 2002).

The men also expressed a mixture of views in relation to their attitudes to same sex relationships. The finding that some of the men have a negative attitude towards male same sex relationships is unsurprising as the population of the South Wales Valley's are not renowned for their acceptance of homosexuals. However, the finding that some men held a negative attitude towards lesbian relationships is interesting given that lesbian sexual activity is portrayed in popular media, such as the highly successful television series 'Coupling' (Moffat 2001), as being the ultimate 'turn on' for heterosexual males.

3.2.8. Socio-sexual education.

This theme is concerned with whether or not participants recall receiving formal socio-sexual education and if so what the nature of its content was. It also explores whether participants have obtained any such education on an informal basis and if so from whom. Finally, it considers the perceived value of such education to the participants.

3.2.8.a. *Receipt of formal socio-sexual education:*

Two thirds of the participants (8/12) reported having received some such education whilst attending compulsory education, that is to say whilst they were at school. Only two participants reported being unable to remember whether or not they had had received such information. One participant had received socio-sexual education at both school and college.

3.2.8.a.i. Content of formal socio-sexual education:

Many of the participants were unable to describe the content of the education they received until prompted by being asked, "*...did it include...?*" However, once prompted in this manner most of the participants then enlarged on the subject as will be described in 3.2.9. (understanding of issues around sexuality)(below). Participants recalled the discussion of six subjects. The subjects remembered by most of the participants were those of contraception and sexually transmitted infections (STIs). Seven of the participants recalled being given information about male changes at puberty, consent, and conception. Only four of the twelve participants recall being given any information about relationships and only one recalled being given information about changes to women's bodies at puberty.

Most of the information received, thus appeared to be about the mechanical and biological aspects of sexuality. The emphasis appeared to be on negative aspects of sexual contact such as teenage pregnancy rates and HIV. In fact, some of the information provided appeared to have been given with a view to scaring participants into not having physical sexual relationships as is demonstrated by the following extract:

R8, Paras. 205 – 208;

Int. *Ok. Did they talk about, have you heard about sexually transmitted infections?*

P8 *Yeah, AIDS an all that, we talked about AIDS an all that.*

Int. *Ok, so what did they tell you about that?*

P8 *Well one of the teachers that was in my class, that I was in, he went over to Africa, you know he went over to Africa when we were all on half term, and um, he come back, he had it on a video an all that. He took his video camera over to show us,* *and then, he was, where he was staying he was asking the people, uh, 'How bad is AIDS over in Africa?' and obviously then the guy that was with him, speaking to him, speaking in the camera was saying its very bad, you know, over one million people died here each, uh, every year, you know and the numbers are growing.*

3.2.8.b. *Informal provision of socio-sexual education:*

Nine of the twelve participants referred to obtaining socio-sexual information outside of the education system on an informal basis. One of the main ways in which they gained such information was through television programmes. Such programmes were varied and included soap operas such as 'Eastenders':

P3; Paras. 236 – 237;

P *Have you heard of HIV or AIDS?*

R3 *Yeah, I know AIDS, yes, Mark Fowler has got AIDS*

Day-time television was another source of such information for some of the participants:

P7, Paras. 236 – 243;

Int. *Can you think about any particular type of TV, can you name a programme?*

P7 *The, um, morning show in the mornings, 'Richard and Judy' and stuff.*

Int. *Right, so they talk about it on there? So 'Richard and Judy' you say.*

P7 *Well they used to be on, but they're not on any more*

Int. *Ok.*

P7 *They talked about agra tablets and stuff.*

Int. *Viagra?*

P7 *Yeah.*

Other participants discussed seeing programmes specifically about sexuality issues. For example participant eleven discussed a programme concerned with asphyxiation and sexual activity, whilst participant nine discussed a programme that discussed the process of conception and birth:

P9, Para. 176;

P9 *I can't remember what it was called, 'The Unborn' or something like that. It tells you physically about a man and a woman and actually shows a man and a woman making love and the fundamentals of it and a baby at the end of it, and you know.*

Three participants gained information from informal sessions held at their youth club. Although such sessions included information on consent and contraception, they appear to have been more positive and concerned with relationships rather than simply outlining the mechanical and biological aspects of sexual behaviour.

Two participants also reported gaining information from magazines. That more of the participants had not obtained information from magazines is not surprising given the fact that most of the participants had limited reading abilities. It is possibly for this reason, that the magazines they reported looking at were not 'mens" magazines such as 'Mens' Health'. Rather, they were magazines such as 'Jackie', a teenage girls' magazine with photo stories about relationships, and 'Take a break' and 'Women's Weekly', both of which contain short stories about relationships. Another reason that they may have looked at these is that they may have been more readily available as is suggested by participant eleven:

P11, Para. 149:

P11 *I looks at 'Take a break', I looks at, Oh, what's the other one, 'Woman's Weekly' an' I got loads of 'Women's Weekly'. What it is, was my mother started me off. She started reading them and if I got bored I picked them up and started reading them.*

Finally, two participants reported receiving some socio-sexual information from their families. In the case of participant four, he merely stated that his sister had shown him how to use a condom. In the case of participant nine, however, his parents appear to have provided him with a reasonable amount of information about the bio-mechanical aspects of sexual development, conception and childbirth in the form of a book written in simple English and a video.

3.2.8.c. Perceived value of socio- sexual education:

Six of the twelve participants expressed the view that such education was important and that they would have like to have received more of it. For some of them, they felt that provision of such information solely at school was not necessarily the best place to be given such information. This appeared to be for two main reasons. Firstly, a number of participants commented on the fact that they had forgotten some of the information and would have liked updates or refreshment. Secondly, some of the participants expressed the view that they may not have been sufficiently mature to understand and assimilate the information when they were presented with it in school:

P10, Paras. 140 – 143;

Int. *Yes. Did you have any sex education at school?*

P10 *Yes, but, there again, I was too ignorant in school. I take, I takes sex education more serious now than I did when I was in school, 'cause I used to lark about then.*

Int. *Right.*

P10 *Cause words in school, like 'an erection', I used to burst out in laughter, but now I take it serious.*

Whilst many of the participants did not express any view about the format of the additional information they desired, some said they would like booklets, videos or an 'expert' to come into their day service. Participants who gave a view as to the content of such information, although they mentioned such things as consent and STIs, also requested information on more positive aspects such as relationships and parenting.

3.2.8.d. Socio-sexual education: Concluding remarks

Whilst two thirds of the participants had received formal sexuality education, the emphasis of this appeared to be on the biological and legal. To some extent it portrayed a pathologised view of sexuality and sexual behaviour by, for example, emphasising negative aspects such as sexually transmitted infections, such as HIV. Moreover, the emphasis was on the male body with only one participant reporting that women's bodies were discussed. The reason for this is not given. One may make assumptions such as that, educators were of the opinion that the men would not participate in sexual activity and therefore any education about such things as relationships and the female body would be superfluous to the men's needs. Although other studies show that such a view may exist amongst parents (see section 1.5.6.), to make such an assumption in this situation would not be appropriate given that there may be alternative reasons such as that the educators are constrained by school governors in what they teach.

Given the limited formal socio-sexual education provided to the participants, it is unsurprising that many of them gained information through informal sources such as television programmes and magazines. Whilst such information may be factually correct and presented in an unprejudiced manner it may equally lead to participants being presented with incorrect information or a biased perspective on some socio-sexual issues.

Despite the fact that we are living in what is often referred to as a 'learning society', it does not appear to be the case that 'lifelong learning' encompasses socio-sexual education for the men with learning disabilities who participated in this study. Possibly this is because the aim of such learning is said to be prosperity for both individuals and the nation as a whole (Riddell, Baron et al. 2001). Men with learning disabilities are not generally seen to contribute to the nation's prosperity. Given this, investing in their socio-sexual education may be seen as providing no economic advantage. However, I would argue that this is short sighted, in that failure to provide such education may increase the likelihood of abuse, sexually transmitted infections and unplanned pregnancy. It is also suggestive of the view that sexuality is an irrelevance to men with learning disabilities and may deny them the opportunity of experiencing positive relationships.

3.2.9. Understanding of issues relating to sexuality:

This theme is essentially self explanatory in that it explores the understanding participants had of a variety of issues relating to sexuality. Whilst many of the subjects are concrete and were discussed in the socio-sexual education they received, some of the subjects discussed were more abstract such as the meaning of 'attractiveness' and 'love'.

3.2.9.a. The meaning of 'sex'

Three participants (participants three, nine and twelve,) were unable to express what they thought sex was. The remaining participants described it in a number of ways. For participants four and eleven, it was predominantly about penetrative heterosexual intercourse, a view not uncommon amongst the general population (Daniluk 1998; Tepper 1999). However, participant eleven did acknowledge that it may also relate to other behaviours:

P11, Paras. 124 – 125;

Int. *If somebody says what is sex, how would you explain sex to somebody?*

P11 *Well, only thing I know is it's mainly a man on top of a woman or a woman on top of a man having sexual intercourse, that's mainly it. () Or people can be touching or kissing, or mainly its like I said.*

Participants five, six, seven and ten also described sex in terms of 'sexual intercourse', 'the full thing' and as 'making love to somebody'. They did not, however, specify the gender of those participating in such acts. Moreover, participants five and seven along with participants eight, nine and eleven described 'sex' as including a variety of other behaviours such as hugging, kissing, fondling, 'touching private places' and masturbating. However, only one participant referred to the fact that hugging may or may not be sexual depending on its context:

P9, Para.130;

P9 *I'd class, like eye contact as a, as part of a sexual behaviour. I class as well touching, sometimes hugging is part of it, I understand with hugs whether, like you hug a family member, I understand that it's normal, but when it comes to a hug with the opposite sex then it's different, you know.*

Two participants, (participants five and nine,) also described it in terms of gender as is demonstrated by the following extract:

P9, Paras. 125 – 128;

Int. *Is it just about a man penetrating a woman or is it other things as well?*

P9 *I think sex is gender.*

Int. *Ok.*

P9 *First thing that comes into my head is man and woman.*

3.2.9.b. Understanding of 'consent' and other legal issues:

Two participants, (participants one and six,) one of whom had a girlfriend, were unable to describe their understanding of consent. The remaining participants were able to describe 'consent' in varying terms. Most referred to it as relating to permission and making sure that someone said 'yes' before 'having sex'. However, only participants four and seven made reference to the fact that such permission should be given freely.

Despite most of the participants seeming to have some understanding of the concept of consent, only two (participants ten and eleven) appeared to be aware that sexual activity with another person without their consent was unlawful.

In fact, participants appeared to have little knowledge of the law except in relation to the age of consent. Five of the participants made reference to the 'age of consent' as being sixteen. However, none referred to the need for a person to have information about the nature of the act they are consenting to, nor to the issue of capacity.

Additionally two of the participants (participants six and eight) appeared to be under the misapprehension that the law required a male to wear a condom:
<u>P8, Paras. 346 – 347;</u>

Int. *Right, ok. I know what we were talking about. I was asking you what you think your Mum and Dad would think if you had a girlfriend.*

P8 *They would think it was alright unless you haven't got protection then it wouldn't be alright. It would be breaking the law.*

Participant eight also appears to incorrectly believe that he would require parental consent as can be seen in the following interview excerpt:
<u>P8, Paras. 360 – 363;</u>

Int. *What would you like to do together? Would you like to live together, get married, would you like to have children?*

P8 *We just, uh, would like to go out and see how things run with it. I wouldn't like to do any of the other things unless I had consent an all that, you know, from their parents, the girl's parents an all that.*

Int. *Right, so it's important that the girl's parents are happy about it as well is it?*

P8 *Yea.*

3.2.9.c. *Understanding of contraception:*

When asked about contraception seven of the participants referred to condoms. They were generally aware of the wide variety of places that one could obtain condoms such as chemists, local shops, pub toilets, and supermarkets. Participant three was also aware that he could get them from his general medical practitioner's surgery. No participants referred to either family planning clinics or genito-urinary medicine clinics where they could obtain contraceptive advice and condoms free of charge. However, whether they would use such services is unclear, as some noted that they would be embarrassed about purchasing condoms over the counter as can be seen in the following extract from the interview with participant nine:

P9, paras. 188 -192;

P9 *I'm a bit wary, if I bought something from Boots, I'd be a bit wary, cause imagine walking up to the counter and saying, 'Can I buy some condoms?'*

Int. *So you'd be shy about that?*

P9 *I'd be embarrassed, I wouldn't be shy, I'd be embarrassed.*

Int. *Ok.*

P9 *But if I was buying them from a toilets or something like that nobody else knows, you're doing it privately.*

Only one of the participants was aware of an alternative form of contraception to condoms, namely participant eight who was aware that women could 'take a pill', but did not enlarge on this.

3.2.9.d. *Understanding Sexually Transmitted Infections (STIs)*

Seven of the 12 participants gave the impression that they had some understanding of STIs. However, all but one of these, participant nine, only referred to HIV and AIDS. Even he did not name any other form of infection, but simply referred to the danger of 'infections like STDs'. Given that the term 'STI' has been used in preference to that of 'STDs' for approximately five years, it is likely that his knowledge of sexually transmitted infections is out of date.

Only five of the twelve participants were aware that transmission of STIs could be prevented by using a condom. More worryingly, one participant (participant eight) appeared to be under the impression that you could be vaccinated against HIV as is shown in the following excerpts:

P8, Paras. 211 – 212;

Int. *So how do you stop yourself getting AIDS?*

P8 *Injections an all that.*

P8, Paras. 284 – 286;

P8 *Sometimes it can be dangerous 'cause the person they have sex with may have AIDS an all that.*

Int. *Right.*

P8 Which means then that the person they've given it to, that they've had sex with, has now got AIDS an' needs a injection, to uh, they'll have to have an injection just in case the person has got AIDS.

Moreover, participants did not appear to be aware where they could obtain information, testing or treatment for STIs.

3.2.9.e. Understanding of Pornography:

Only three of the participants (participants two, seven and nine) were able to explain or describe pornography without further prompting. Two of the participants (participants eight and ten) appeared to confuse pornography with paedophilia as is demonstrated by the following extract from the interview with participant ten:

P10, Paras. 236 – 239;

Int. *Ok. If I ask you what pornography is can you tell me?*

P10 *I can actually tell you.*

Int. *Ok. So what would you say pornography is?*

P10 *It's people that are interested in children.*

3.2.9.f. *Perception of sexual activity as dangerous.*

Participants were asked whether or not they felt that sexual activity could be dangerous. Participant three was of the impression that all forms of sexual activity were unsafe. Two participants (participants four and eleven) stated that they were not sure whether sexual activity could be dangerous and participant two did not think that it could be dangerous in any way.

The remainder of the participants thought that sexual activity could be dangerous in one of two ways. Participants one, five, seven, eight and nine thought it could be dangerous from the point of view of contracting a sexually transmitted infection. Participants six and twelve thought it could be dangerous from the point of view conception. Finally participant eight believed that having a relationship with someone was so dangerous that it wasn't worth the risk:

P8, Paras. 317 – 320;

Int. *So would you like a girlfriend or a boyfriend?*

P8 *No.*

Int. *No?*

P8 *'cause I wouldn't like to get into trouble with the law an' all that it's too risky, I wouldn't risk it. If I had the protection I would do it, but other than that I wouldn't, 'cause it's so dangerous.*

3.2.9.g. *The meaning of 'attractive'*

Participants were asked what they thought made a person attractive in their eyes. They responded in three main ways. Firstly, participants four, five, eight and nine said that physical appearance and grooming made a person attractive to them and referred to such things as hair colour, weight, smile, dress style and smelling pleasantly. A second group of participants, namely participants six, ten, and eleven thought that it was a person's behaviour, personality or abilities that made them attractive. They referred to such things as whether the person is fun, is kind and whether they like animals. The final type of response was a mixed one. For example, participants seven and twelve thought that it was a combination of appearance and personality that resulted in a person being attractive, whilst participant three thought it was a combination of being slim, smelling nice and buying the other person chocolates.

3.2.9.h. The meaning of 'love'

Given that 'love' is a difficult concept to define, it was not expected that many of the participants would respond to the question, '*What does love mean to you*? Two participants (participants two and three) did have difficulty explaining the concept and simply stated that:

<u>P3, Para. 367</u>

P3 *Love is when you love people.*

However, a further nine of the participants sought to explain their understanding of love.

Two participants, (participants nine and ten) were somewhat cynical about the idea of love and felt it was just an expression expected of them by their partner:

<u>P9, Paras. 287 – 292;</u>

Int. *Ok. If somebody says they love you what would that mean to you?*

P9 *() I class it as a game.*

Int. *A game?*

P9 *Yes.*

Int. *In what way?*

P9 *They say 'I love you' and I'd go along with it to, so I class it as a game type of thing, 'I love you', 'I love you too' type of thing, I wouldn't class it as serious.*

The remaining participants, however, generally saw 'love' as a positive phenomenon:

<u>P8, Paras. 331 – 334;</u>

Int. What if the girl turned around to you and told you that she loved you. What would that mean?

P8 That would mean, it's a good sign that the relationship is good.

Int. Ok, so what is 'love' then?

P8 Its, uh, something between a man and a woman and you can, its, uh, quite good.

Participant 11 expressed his belief in 'love at first sight':

<u>P11, Para 201 – 202;</u>

Int. *So can you explain to me what love means to you and what's special about the relationship with her?*

P11 *Well () I can't exactly 'splain it, cause the first day I met her, on that Friday, I just said to myself, that's the girl I want to be with...*

However, he additionally, along with participant six, emphasised material aspects of a relationship such as the presentation of tokens of love:

<u>P11, Para. 203</u>

Over the last five years she's been like giving me presents, I've got tapes off her, Christmas cards, I've got three, um, backpacks of the stuff she's give me over the last five years.

Participant five described it in what might be considered traditional idealised terms of giving to, and caring for the other person:

<u>P5, Paras. 334 – 335;</u>

P5 *I wouldn't want nothing to happen to her anyway. I think if anything happened to her I would, no I don't know how I would (interruption - door opens and closes)*

Int. *You say you love her, what does love mean to you?*

P5 *Um, affection for another person, and, um, I'll do more, mostly anything for her.*

Int. *Ok.*

P5 *I'll be her, like I told her, I'll be like her knight in shining armour no matter how we stand.*

Three participants, (participants one, seven and twelve) expressed the view that love meant that you wanted to spend your life with the other person, as participant seven said:

<u>P7, Para. 307;</u>

P7 *You're always thinking about the other person and they always want to be with each other, an' you look after each other and you don't hurt each other.*

Such a variety of views are not confined to the participants of this study and can be found amongst the majority population and in literature.

3.2.9.i. Understanding of issues relating to sexuality: Concluding remarks

Despite two thirds of the participants having received some formal socio-sexual education, their knowledge and understanding of some relatively concrete issues such as, the law relating to consent, forms of contraception other than condoms, sexually transmitted infections (excluding HIV), pornography and availability of genito-urinary services was at best limited and in some cases incorrect. Why this might be is unclear, it may be due to such socio-sexual education having taken place in the distant past and/or at a time when participants were unreceptive to such information. Another alternative is that the information given may have been limited and presented in a manner which was inappropriate to the participants' cognitive, communicative or other abilities.

Despite the fact that complex concepts such as attractiveness and love were not reportedly discussed in their formal socio-sexual educations sessions many of the participants were willing and able to explain their understanding of these concepts. This supports participant's reports that they gained much of their information about sexuality issues from informal sources such as family, the television and magazines.

3.2.10. Sexuality – Attitudes, behaviour & experiences:

This theme follows on from the previous two themes and explores the attitudes participants held towards certain issues and their actual behaviour and experiences. It commences by considering whether men with learning disabilities are sexual beings and the extent to which participants perceived themselves as having control over their sexuality and sexual behaviour.

3.2.10.a. Men with learning disabilities as sexual beings?

Whilst many of the men implicitly described themselves as sexual beings throughout the interviews, only two participants (participants four and ten) specifically made reference to being a sexual being. Their view was that they were, as is made clear in this extract from participant ten:

P10, Paras. 137 – 139;

P10 *Well, I, as you are doing a survey about sex I do have feelings, I do have, can I say?*

Int. *You say what ever you want, however you like.*

P10 *I do get a, a hard on.*

That men with learning disabilities are sexual beings is generally recognised in the literature (Reid 1995; Wheeler 2001) and should not therefore come as a surprise to the reader. However, they may not develop at the same time as non-learning disabled peers. For example, it is generally recognised that people with Downs Syndrome and people with more severe learning disabilities develop sexually later than people with mild learning disabilities (Mosier, Grossman et al. 1962; Mitchell, Doctor et al. 1978; Chapman and Pitceathly 1985). However, as noted in section 1.5.7. few studies have previously sought to ascertain the views of men and women with learning disabilities themselves as to this question.

3.2.10.b. *Perceived control over sexuality and its expression:*

Despite participants asserting their belief that they were sexual beings, the extent to which they felt they had control over their sexuality suggests that other people did not necessarily hold this view. Alternatively they may have held the view that participants' expression of their sexuality was either dangerous or inappropriate, a view supported by the findings reported at section 3.2.10.c below. Whilst everyone is 'controlled' in the expression of their sexuality by laws and social mores, the men in this study perceived the expression of their sexuality to be controlled by a variety of additional factors.

One of the main reasons participants felt constrained was due to a lack of privacy, whether this was in their home or at their partner's home, as was the case for participant one who stated that he had not had the opportunity to do more than kiss and cuddle his girlfriend because:

P1, Paras. 252 - 254

P1 *I didn't feel I could do it.*

Int. *Is that, why was that do you think, was it at her house?*

P1 *Yes, and perhaps her parents would be there and walk in.*

A further reason why participants perceived themselves to have little control was the fact that their parents, families or paid carers were seen as being able to determine whether or not participants could express a sexuality other than a limited form of heterosexuality. That is to say, parents, families and paid carers were seen as being able to control whether a person's relationship was sexual and whether it was allowed to develop, as can be seen in the following extracts:

P3, Paras. 276 – 281

Int. *Ok, so do you think that at sometime you'd like to have sex with your girlfriend?*

P3 *No, no.*

Int. *Why's that?*

P3 *I'm not allowed.*

Int. *You're not allowed?*

P3 *No.*

P12, Paras. 305 – 312;

Int. *So you'd like to live with her, maybe get married and you'd like to have children?*

P12 *Um.*

Int. *Do you think that might happen or do you think there are things that might stop you?*

P12 *It might happen, it might not. It depends.*

Int. *What sort of things does it depend on?*

P12 *My father, my Aunty, my Cousins. My Cousins are over protective of me.*

Int. *Yes?*

P12 *Very.*

Other factors that were seen to constrain participants' ability to develop personal and intimate relationships were limited finances and a reliance on others to support or transport them either to places where they might possibly meet a potential partner / friend or to a place where they could meet up with an existing friend or partner. Both such issues were discussed in section 3.2.4. Overall, the findings in this section are similar to those of the studies discussed in section 1.5.7. which were that women and men with learning disabilities had little personal control over the expression of their sexuality. Rather, others, such as parents and carers exerted control over them.

3.2.10.c. Participants' experience of consensual sexual activities

Given the various constraints placed upon the participants' sexual expression, it is hardly surprising that only three participants (participants two, five and eleven) stated that they had experienced consensual sexual intercourse (one participant discussed what he suggested was non-consensual sexual activity, but this will be discussed in section 3.2.14.) For most participants their sexual activities were limited to holding hands, kissing, talking and cuddling. This finding is similar to the findings of Heyman and Huckle (1995) and Lesseliers (1999) as discussed in section 1.5.7.

3.2.10.d. Attitudes towards 'sex' and specific sexual behaviours:

Participants were asked whether they thought 'sex' is ok and if they considered any types of sexual behaviour were wrong.

Participant three was the only person to state that he thought all sex was bad. This was due to a belief that it was unsafe.

Five of the participants thought that 'sex' was 'ok', though four of these qualified this. Some of the qualifications may be considered straightforward and demonstrative of the participants having taken on board the socio-sexual education messages they had received. For example, participant one said that sex was ok as long as you used 'precautions' whilst participant eight expressed the opinion that it was 'ok' as long as you had obtained consent. However for some of the participants the qualification they placed on the concept of 'sex' being ok suggested that that had been given the message that it was wrong or that at best it was something that shouldn't be publicised:

P2, Para. 275;

P2 *Sex is alright as long as you keep your mouth shut, keep your mouth shut, keep it to yourself.*

Such a view appears to be commonly held by men with learning disabilities possibly as a result of the socio-sexual education they have received and their socialisation, as discussed in section 1.5.6. However, it is not an uncommonly held belief amongst the general public (Leiblum 1998).

Participant four was the only participant to describe 'sex' as more than 'ok' stating:

P4, Para. 131;

P4 *Well, I like sex.*

In relation to the participants' view on whether some sexual behaviours were wrong, four participants expressed the view that all forms of sexual behaviour were 'ok' as long as they were lawful. For example, participant seven noted that if violence or force was involved the activity would be wrong.

Participants five and eight expressed what be might be seen as a liberal view in so far as they suggested that as long as the act did not interfere with another's rights and it took place in private, then it was acceptable. This can be seen in the following extract from participant eight:

P8, paras. 275 – 276;

P8 *It's their decision as well if they want to do it or not.*

Int. *Ok. So basically you're saying sex is ok as long as...*

P8 *Protection is there with you, it is important with it, and people are happy about doing it and it's in private...*

Other than homosexuality, to which participants expressed mixed views and which has been discussed previously in section 3.2.7., the only lawful sexual activities described as wrong were bondage and sadomasochism[30]. Four participants (participants five, nine, eleven and twelve) described these as wrong. However, even though participants saw such behaviours as wrong, some, such as

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[30] Following the case of R v Brown (1994)1 A.C. 212. it would appear that consensual sadomasochistic acts are unlawful when performed by homosexual men. However, such acts have not, to the author's knowledge, been prosecuted in relation to consenting heterosexuals.

participant five, still felt that such activities should be left to the choice of the individuals concerned:

P5, Paras. 233 – 235;

P5 *Some sexual behaviour can be formed behind closed doors as long as it's in the right manner. You wouldn't do something in public or to make the public eye aware, you know, you do what ever you do behind closed doors.*

Int. *Ok. Do you think that some kinds of sexual activity, or sexual behaviour as you said, are wrong?*

P5 *Yes, I think its wrong, like, um, bondage, people in bondage, I think that's wrong where they are tying people up, but that's everybody's way in it? I can't say you can't do that because it's wrong.*

The participants in this study would appear overall to hold more liberal views towards sexual expression and activities than those in the studies reported by Edmonson and Wish (1975), and Konstantareas and Lunsky (1997) as discussed in section 1.5.7.

3.2.10.e. Participants' attitudes and behaviour in relation to condom use.

Of the three participants who stated they had experienced consensual sexual intercourse, two (participants two and eleven) stated they had worn condoms when they had sexual intercourse. Participant five, despite being aware of the risks of unprotected sex stated that he would not wear one and gave the following explanation:

P5, Paras. 258 – 259;

Int. *What about / you said that some people could have infections. One of the things about condoms is they can stop you getting infections, so you'd never think of using a condom?*

P5 *I'd never use a condom, um, I used it once, I used a condom once and it just made my stomach bloat, um and I had pain in my groin when I was using it so I don't use one.*

Two other participants discussed whether they would use a condom in the event that they had sexual intercourse. The first, participant nine stated that he would use them if he could obtain them from a toilet but that he would be too embarrassed to purchase them from a shop. The second, participant twelve, was only willing to commit himself to using them for a short period of time:

P12, Paras. 241 – 242;

Int. *Ok. Supposing you start going out with the girl you like and you have a relationship with her would you use a condom?*

P12 *Yeah for the first few weeks and then see what she says after.*

Why this is the case was not discussed. However, it may be that he believed that they were not necessary in a monogamous relationship. This was found to be the case in a study of condom use amongst homosexual men by Flowers et al (1997).

3.2.10.f. Participants' attitudes to and use of pornography:

Although the majority of the participants were unable to define or describe pornography (see 3.2.9.e.) once they were given examples of pornographic material, eleven participants stated that they had seen such materials. Two of the participants (participants three and eight) expressed the view that in some way it was wrong. For example, participant eight related an occurrence at his residential 'college' when a couple of his peers had accessed a pornographic web site. Because he thought it was wrong and might have had implications for the whole class being disciplined he reported his peers to a 'houseparent'.

Whilst not stating that use of pornography was wrong, three participants (participants four, seven and eleven) implied that they were concerned that other people should not be aware that they used it. For example, participant eleven described the embarrassment he felt when purchasing pornographic magazines:

<u>P11, Para 152 – 155;</u>

Int. *Did you buy your own or get them from friends?*

P11 *I gets my own if I can. I do intend to get embarrassed so if there's people in the shop I don't buy them.*

Int. *Ok.*

P11 *What I do is I wait and then if there's no-one in the shop I buys it then. I gives the bloke the money, puts it in my pocket and runs out of the shop quick.*

Similarly, although participant seven stated that he watched pornographic programmes on satellite television, he said he would not purchase any pornography due to the likely reaction from his mother:

P7, Paras. 274 – 279;

Int. *Ok. Have you ever been out and bought DVDs or videos yourself or magazines?*

P7 *No if I did it would get chucked, my mother would chuck it out.*

Int. *Right, so your mum wouldn't be very happy about that?*

P7 *No.*

Int. *Has she said to you that she doesn't like stuff like that then?*

P7 *Yes.*

Participant seven also thought that pornography was not realistic, a view echoed to some extent by participant six who expressed the view that pornography was rubbish and not worth spending money on.

The remaining participants were more open about their use of pornography. For example, three participants (participants two, five and twelve) had viewed such materials with other people such as their girlfriend or a person they were sharing accommodation with. In these cases, it was unclear whether the pornography was used predominantly as a sexual stimulus or in order to gain information about sexual activities. For example participant five, who had watched pornography with his house-mate, stated:

P5, Para. 221;

P5 *I watch the porn channels, where you can pick up extracts. I write it down, I've got a note-pad. I write it down and think 'Oh that's a good idea', 'that's a good position' or something.*

In fact, only two of the participants (participants nine and twelve) stated that they used pornographic materials as a sexual stimulus prior to masturbation. For example, participant nine gave the following reply when asked whether he used pornography to become sexually aroused:

P9, Paras. 200 – 202;

P9 *Um, I do watch, I do watch some, um, like sex films on channel 5 on a Friday night. I get aroused by watching them. I get aroused, um, I got uh, how can I say it, a cock mag. I keep one in the bath room to get aroused.*

Int. *And then you masturbate?*

P9 *Um, yes, if I can't get enough out of that, I jump in the bath and masturbate.*

3.2.10.g. Sexuality – Attitudes, behaviour & experiences: Concluding remarks

One is presented with the situation in which the participants, although they consider themselves sexual beings, feel they have little control over the expression of their sexuality and minimal opportunities to participate in sexual activities. Given this, it is not unexpected that for most of the participants their sexual experiences were limited to such behaviours as kissing and cuddling. Nor is it surprising that only three of them describe having experienced consensual sexual intercourse. Equally, given that most of the participants resided in the family home it was not unanticipated that so few accessed pornography or wished to ensure that others were not aware of them doing so. In relation to those who felt negatively about purchasing or otherwise accessing pornography, it is not clear why this was the case although both societal and parental views appear to have influenced their beliefs.

3.2.11. Experiences of, aspirations towards and attitudes to personal and intimate relationships:

Of the twelve participants, six stated that they had a personal and intimate relationship with another person. In all cases, this person was female and was referred to by the participants as their 'girlfriend'. This theme initially discusses the experience of those who had a girlfriend at the time of them being interviewed. It then focuses on the other six participants and considers their desire for a personal and intimate relationship and the desired attributes of such a person. The question of whether the men felt that they had a right to such relationships is considered along with issues such as marriage and perceived need for support within such a relationship.

3.2.11.a. Having a girlfriend:

Participants one, two, three, four, five and eleven stated that they had a girlfriend. The duration of such relationships varied considerably. The shortest being one month and the most enduring being eleven years. Other than participant three, however, all had been in the relationship for a year or longer. Participant two, who had been going out with his girlfriend for eleven years was the only participant who was engaged to be married.

All of the participants with girlfriends had met them in a setting provided for people with a learning disability. Two had met their girlfriend at school, two at a Gateway Club, and one each at a day centre, and a youth club.

Those participants with a girlfriend were asked what was special about having a girlfriend and how their relationship with their girlfriend differed to their relationships with other friends. Only participant one had difficulty in expressing an answer. However, whether this was the complexity of the question or whether his answer is in fact a considered response is unclear:

P1, Paras. 384 – 387;

Int. *Ok. So what is it that's special about your relationship with your girlfriend that's different to your relationship with other friends?*

P1 *Um, huh, I can't really think, um...*

Int. *That's all right, what is special about her, why did you end up going out with her and not someone else?*

P1 *Because she liked me and these other girls didn't*

The other participants described a range of things that were special about their girlfriends. They included such things as the way they helped each other (participant eleven), the person's warmth and personality (participant five), their willingness to listen and act as someone they could trust and confide in (participants four, five and ten) and their appearance (participant three). This is similar to the findings of Lesseliers (1999) and Mattinson (1970) who noted that people in their studies expressed love in terms of doing things with a person, being nice to them or taking care of them.

Participants were asked to describe the frequency with which they met their girlfriends. They were also asked what things they did with their girlfriends that they did not do with other friends. Of those participants who responded to the first question only one (participant eleven) regularly saw his girlfriend outside of some form of provision for people with a learning disability. He discussed going on long walks together, visiting the local beach and the fair during the summer months. He also said that they visited each others homes frequently, went to the cinema occasionally and to one of the two nearest cities on a monthly basis. Additionally, they went to steam rallies with her family and / or his father. The remaining participants, including participant two who was engaged to his girlfriend, only met their girlfriends one or two times a week, either in a day service setting or at an organisation for people with learning disabilities.

In relation to the activities participants carried out with their girlfriends, these were quite limited and often took place in the company of others. For example, participant one who went swimming and to the cinema with his girlfriend rarely saw her outside of the two organisations they attended. Swimming was carried out with other members of the organisation, as were visits to the cinema, although they did sometimes see a different film to other members of the organisation when they went to the local multi-screen cinema. Likewise, participant two, despite the fact he was engaged, his girlfriend was pregnant and they intended to move into a house together within a matter of months, describes the limited activities he regularly undertook with his girlfriend:

<u>P2, Paras. 142 – 155;</u>

Int. *You know you've been going out with your girlfriend for about 11 years, what sort of things do you do together? Do you go...*

P2 *Like shopping, the two of us go shopping and a cup of coffee.*

Int. *So do you do that very often?*

P2 *Yes. The two of us go out with staff.*

Int. *Every day, every week?*

P2 *Monday, Friday.*

Int. *A couple of times a week then?*

P2 *Yes, we ask the staff if we have money and ask them to go to town and shop and buy things.*

Int. *(Sneezed)*

P2 *I tell them we will be back in about ten minutes and we have a coffee and tea, and coke. Then we look around the shops and buy things and we are back about ten past three and then we walk back into the centre.*

Int. *Do you go out to the pictures together or go out for a meal?*

P2 *Just shopping an' that.*

Int. *So when you go out together you mainly go shopping?*

P2 *And for a cup of coffee and tea an that.*

From the above, it can be seen that opportunities for privacy and intimacy were generally quite limited. On the occasions that participants were able to visit or were visited by their partners at home the amount of privacy they were given varied. For example if participant eleven was visited by his girlfriend at his home they were not afforded any privacy. However if he visited his girlfriend at her home, then her parents promoted the idea of them having time alone together:

<u>P11, Paras. 208 – 209:</u>

Int. *() Going back to your relationship with A, do you get much time on your own together? You said you only see each other once a week now, but can you be on your own in private?*

P11 *I don't know. When we're up my house we don't get no privacy, but in her house we always get privacy. We're down stairs for about an hour and her father says 'why don't you two go upstairs?' That's what we does, we lays on the bed, listens to music, or watch videos. She tells me all the gossip what's happening in the care club or loads of things she tells me.*

Even those participants living on their own or in supported accommodation had difficulty in finding opportunities to spend time together alone with their girlfriends. For example, although participant five had been advised by his support workers that he could take people home, he was unable to take his girlfriend home:

<u>P 5, Paras. 322 – 329:</u>

Int. *Ok. So all you do at the moment is see each other at work?*

P5 *Yeah.*

Int. *You said you kiss and you cuddle. Do you ever go out together to the club, pictures or anything?*

P5 *No she's not allowed out after dark.*

Int. *She's not allowed out after dark?*

P5 *No.*

Int. *Right, what about in the day time, do you ever go out together or...*

P5 *No, I meet her in town with her mum, you know. E is very shy, she's a very shy person and she can get really intimidated. She likes to know where she is going and who she is going with and things like that.*

Likewise, participant four was rarely able to visit his girlfriend in her supported accommodation due to staffing issues. However, neither was she able to visit his home due to staff apparently being concerned about risks that they had not clearly explained to participant four. (His girlfriend used a stick and was in need of a hip replacement.)

P4, Paras. 286 – 294;

P4 *It is a problem, they don't bring her round to see me.*

Int. *Why do you think that is?*

P4 *I don't know why.*

Int. *Have you asked them if they'll bring her round?*

P4 *Yes.*

Int. *And they said no?*

P4 *They can't trust T.*

Int. *Did they say why that was?*

P4 *huh, they saying () they saying I can't cope with T because she's a bit older.*

For most of the participants, as a result of a lack of opportunity to be alone, acts of intimacy were predominantly limited to talking together, holding hands, dancing, kissing and cuddling.

Despite the difficulties faced in maintaining or developing personal and intimate relationships, two of the participants in particular demonstrated considerable resilience in their relationships. Participants four and eleven discussed some aspects of communication within their relationships and in particular the way they resolved difficulties. As discussed above, participant four rarely saw his girlfriend outside of Gateway Club and stated that he found it hard to communicate because of this. However, they phoned each other on a regular basis and when at

Gateway Club he would sit and help her with her embroidery whilst talking to her. He also emphasised the importance of giving her time to think about suggestions he proposed to her:

P4, Para. 162;

P4 *I give my partner some spare time to talk to me, to each other, and go from there, what she wants and what she doesn't want.*

Participant eleven, who had been in the relationship with his girlfriend for five years was able to see his girlfriend more frequently. However, his father was not in favour of the relationship and on numerous occasions had suggested that it be terminated. Participant eleven described how he dealt with this in the following excerpt:

P11, Paras. 65 - 67

P11 *But for some reason my father do not like, like my girlfriend.*

P *Right.*

R11 *I think what it was, he used to like her but ever since her mother chucked me out he gone to dislike, but I said, 'Look', I said "cause her mother chucked me out there's no need for you to dislike her'. I said, 'tough, you'll have to get used to me and her being together, we've been together five years', but he keeps on to me, the last five years, 'get rid of her, get rid of her'.*

He also described his relationship with his girlfriend as one in which there were numerous arguments. He stated his girlfriend had a temper and described the way in which she went upstairs and slammed doors. He expressed the opinion that his girlfriend had learned such behaviours from her mother. He described how he attempted to use the same methods of resolving such occasions as his girlfriend's father did with his wife:

P11, Para. 74;

When her mother goes up (goes upstairs and slams doors, etc) her father goes up to try and calm her down so when A goes up I tries to calm her down. I don't, I've never hit her, I say to myself don't do it cause if you do it once you'll do it again.

On occasions, this intervention was effective. However he also described how, at other times he resorted to threatening to terminate the relationship:

P 11, Para. 75

P11 *I used threatening words against her, if she has a bad mood on her I say 'look if you carry on me and you are finished, we'll never get married, I'll be off out, get my money off your mother and you'll never see me again'. On that she just calms down straight away. I told her father I did it and he said 'good you've got to do something like that just to calm her down'. If she thinks you're not taking no notice of her she calms down after, but if you take notice of her she'll carry on and on and on and she does my head in after a while.*

This may not be perceived as the ideal way of maintaining a relationship. However, it demonstrated that despite receiving little in the way of formal education on relationships participant eleven was able to use various means in order to resolve conflicts within the relationship.

3.2.11.b. Desiring a personal and intimate relationship:

Out of the six participants who at the time of the interviews were not in a personal and intimate relationship, only one, participant eight, stated that he did not want a girlfriend or boyfriend. The remainder expressed the view that they would like a personal and intimate relationship at some stage in their lives.

They then discussed the desired attributes of such a person. These were essentially the same attributes as those participants described as being attractive, as discussed above in section 3.2.9.g. Some participants emphasised the preferred personality of a potential partner. For example, participants seven and ten wanted a relationship with someone who was kind. Other participants placed greater emphasis on the, would be, partner's physical appearance. For example, participant nine expressed a preference for short haired blondes. The only additional attribute that was discussed by two of the participants (participants nine and ten) was the age of a potential partner. Participant nine who was 24 years old said that he would prefer to go out with someone between 18 and 25 years of age, and participant ten who was 25 years of age wished to go out with someone in their twenties.

3.2.11.c. The right to a personal and intimate relationship

In view of the fact that eleven of the twelve participants either had a personal and intimate relationship with someone or expressed the desire for such a relationship, it is not surprising that seven of the participants discussed their belief that they should not be prevented from so doing. Six of the seven discussed this issue in terms of rights. For example, participant four said:

<u>P4, Para. 368;</u>

R4 *I think it's my rights and my girlfriends rights, its not staff's business. It's personal.*

Moreover, in addition to asserting their right to a relationship, some participants recognised that relationships also involved responsibilities. An example of this can be seen in the following extract from the interview with participant five:

<u>P5, Para. 393</u>

Int. *What sort of things do you think are the most important things to tell carers if you want to have a relationship?*

P5 *Tell them to be aware of the fact that we should have the right and respons / the right and responsibility to have a relationship and not to be downgraded and led to believe that we can't have any sort of relationship. You know everybody walks through life, you know, there's all walks of life and we're no different to anybody else, we feel that anybody who has a learning disability should have the right and responsibility to live their life the way they want to and to, um, have their say in which way they want to live their life.*

Additionally as will be discussed shortly in section 3.2.11.e. a number of the respondents recognised that they would need support in such a relationship.

3.2.11.d. Attitudes to Marriage and living with a partner:

All twelve participants were asked about their future aspirations concerning personal and intimate relationships.

Participant ten stated that if he met the 'right person' he would like to live with them. Three participants (participants six, seven and nine) expressed the view that they would like to live with their partner prior to marriage. The reason given by all three for this choice related to obtaining better knowledge of the person prior to marriage as is demonstrated in the following extract from participant six:

P6, Paras. 340 – 341;

Int. *Ok. Would you like to get married or would you just like to live with them or...*

P6 *Get to know them first before going into any kind of the marriage or anything like that, get to know the person at least for a year or something, or two, 'cause all the puns they could argue and that'd be it, bags packed and that'd be it.*

Other than participant three who did not wish to marry or live with a partner, the remaining participants expressed the view that they would like to get married at some point in their lives. This finding, that a large number of the men expressed a wish to marry is not dissimilar to the findings of previous studies discussed in section 1.5.7.

Some of the participants who wished to marry expressed this view in the 'ideal' romantic notion as can be seen from the following extract from participant seven:

P7, Paras. 321 - 322

Int. *Ok. So you'd like to go to the pictures and that sort of thing. If you got on really well with them and thought they were very special and you loved them what sort of things would you like to do then?*

P7 *Have children, get married and have a happy live.*

This finding is similar to that of Scior (2000) who found that many of the women she interviewed subscribed to such a romantic notion of heterosexual love and marriage. However, despite most participants wishing to live with their partner or get married, few felt that it was likely to happen in the near future or without some changes in their circumstances. For example, participants one and eight felt marriage unlikely until they had accommodation of their own, Participant five expressed a need for support for his partner and participant ten thought that due to the level of support he required he would never live with a girlfriend:

P10, Para. 333 – 342;

Int. *If you had a girlfriend would you like to live with her or get married?*

P10 *Live with her*

Int. *Ok. Do you think that might happen?*

P10 *No.*

Int. *Why don't you think that'll happen?*

P10 *Because I need a lot of personal care, someone to get me up and put me to bed.*

Int. *And how do you feel about that?*

P10 *Fine.*

Int. *So you don't think you'll ever live with a girlfriend?*

P10 *No, if I'm honest, I can see myself living with Mam or in residential care.*

3.2.11.e. Perceived need for support in relationships:

As mentioned at the end of the last section, some of the participants expressed the view that they would benefit from support in their relationships. This section outlines the types of support the participants felt would be appropriate. All of the participants expressing a desire for support wanted support with practical manners such as dealing with bills, shopping, reading recipes, and in caring for their partners. Only participant eight was of the impression that he would not require any support.

3.2.11.f. Feeling able to talk to someone about relationships:

Many of the men appeared to have difficulties in being able to talk to someone about their relationships, experiences and feelings. For example, participant five felt unable to talk to his family or friends about his feelings that he might be transsexual or gay. Likewise, he felt unable to talk to them about an incident which occurred that he interpreted as abusive. Even more concerning is the fact that he reports his social worker appeared unwilling to discuss this issue with him as seen in the following extract:

P5, Para. 169

P5 *But its, it was over Christmas when it happened and like my social worker said, 'You should have said something in the beginning so we could have done something about it, but now its been left, and only now you're speaking out about it'. But like I told him, I've been finding it really hard to speak out.*

Int. *I can understand that.*

Others felt unable to talk with support staff in the day services they attended. However, two participants (participants seven and ten) did feel that they could speak to one or both of their parents and that their parent(s) would be supportive. A further three (participants eight, ten and twelve) felt able to discuss such issues with one of the voluntary workers at the organisation they attended.

3.2.11.g. Experiences of, aspirations towards and attitudes to personal and intimate relationships: Concluding remarks

Hopes and aspirations of the participants in this study were not out of the ordinary. They were things which many of the population take for granted, such as the opportunity to develop and maintain relationships. This finding echoes that of Owen in her study of vulnerable adult women (2001).

Despite such aspirations not being unusual, the fact that many expressed realistic views about the support they would require in order to develop and/or maintain a relationship and over half of them believing they had a 'right' to such relationship many of the participants felt that they were not achievable. Although the reasons outlined for such beliefs varied, none would be insurmountable if appropriate accommodation or support was made available.

3.2.12. The context of parenting by men with learning disabilities:

This theme is concerned with the issue of parenting. It considers the desire of participants to parent and whether they feel that such desires are realistic. It then outlines any parenting knowledge participants may have discussed and what they perceived their role in parenting to be. Finally, it considers the support they felt they may need.

3.2.12.a. Parenting desire:

Only participant three expressed the view that he definitely did not wish to have children. He said that this was simply because he does not like children. Two participants expressed the view that they were unsure whether or not they wanted children. For participant twelve, this was because he did not at the time have a girlfriend. Participant eleven, however, appeared to want children but did not think it would be physically possible for his girlfriend:

P11, Para. 234 – 239;

Int. *How about getting married and having children, do you think that'll happen?*

P11 *Married, I reckon that'll happen, but I'm not sure about having kids though.*

Int. *Ok, so why aren't you sure about having kids?*

P11 *I know we are talking about it, but, it's ah, to do with my girlfriend. It's you know these women's problems, she's not coming on regular, and I think we won't be able to have kids.*

Int. *But you'd both like children would you?*

P11 *Yeah.*

The remaining participants expressed a desire to have children at some point in their lives, a finding similar to that of Alderson (2001). However, only one of the participants expressed his reason for wanting children:

P5, Para. 379;

P5 *I'd like to have somebody left in my, um, you know, I'd like to have a child that could live after me I could remember him, you know...*

Having expressed a desire to parent, participant five along with participant ten expressed the view that they did not think this was possible due to their learning difficulty as is seen in the following extracts:

P5, Para 379 – 382;

P5 *...it's no way I'd be able to have a child.*

Int. *Why do they say that?*

P5 *Because of the way I am and ()*

Int. *Because of your learning difficulty?*

P5 *Because of my learning difficulties and how the child would respond to the learning difficulties.*

P10, Para. 91;

P10 *My mother said to the doctor 'will he be able to have children' and the doctor said 'I don't know I can't answer that', but I'm saying 'no' because I've got to be grown up about it, I can't look after children.*

3.2.12.b. Others attitudes to men with learning disability parenting

The majority of participants felt that other people, particularly people who did not know them well would think it wrong for them to have children:

P.7, Paras. 334 – 339;

Int. *How do you think other people would think about you getting married and having children, do you think...?*

P7 *Some people would think it won't be right and some will think it doesn't matter, it's up to the person.*

Int. *Thinking about the people who might think its not right, why do you think they think that?*

P7 *They don't know me do they.*

Int. *No, so why would they think it was wrong?*

P7 *() Because I got a learning difficulty and stuff.*

This finding is similar to that reported by Waxman (1994) who reports that over seventy five percent of the American population are of the opinion that women with disabilities should be prevented from having children.

However, two participants were more positive. The first, participant two, who had been in a long term relationship for eleven years was due to become a father. Although the pregnancy was not planned, he stated that other people were alright when they found out and that both he and his girlfriend were happy about the prospect of them becoming parents. The second participant, participant eleven looked after his cousins every Friday evening and his girlfriend worked part time in a play school. He described what his girlfriend's father said to him about them being able to have children:

P11, Para 241;

P11 *I'm looking after my cousins every Friday night and they're a pair of rascals they are, but I manage anyway. I was talking to her father and he said, 'if you can* *handle those rascals of your cousins and she can handle the play school kids, then obviously you can handle it'. I absolutely adore kids.*

3.2.12.c. Participants parenting knowledge and their perceived role in parenting:

Participants were not asked about this specifically. However, three made comments relating to these issues.

Two of the participants (participants two and four) expressed concern about what they would do if their children became ill. On being asked what they thought would be appropriate, participant two stated that he would call an ambulance and participant four said he would take the child to hospital. Participant two, did however, also state that he would like to know more about the children's medication as he felt this was important in being a parent and developing and maintaining independence.

Participant ten recognised not only the pleasant side of having children, but also some of the responsibilities that accompany parenting stating:

P10, Para. 328;

P10 *I, think () I think, I think to be truthful I think having children is great but you're so tied then aren't you. You got to be home at a certain time and put dinner on the table...*

In relation to their perceived roles in parenting, participants two and four talked about some of the responsibilities they would take on. These included, feeding, changing, taking the child out in a pram for walks, learning about the child's medication, and helping the child with homework.

3.2.12.d. Support for parenting:

Participants were asked if they thought they would need any help or support in the event that they had children. Four of the participants (participants one, two, eleven and twelve) thought they would manage without help. Participant one did not expand on this, but participant eleven explained that both he and his girlfriend had experience in caring for children as described in section 3.2.12.b. above. Despite stating that they could manage without help, both participants two and twelve thought that bringing up the first child might be hard and participant two stated that he would receive informal support from his sister who lived locally.

The remaining seven participants who discussed the issue initially only expressed the view that they would like support from their parents and wider families. Participant seven explained why he would like his parents to support him:

P7, Para. 345;

P7 *My parents and stuff, cause they, they um, they've had children so they know what to do and stuff.*

It was only when participants seven and eight were asked if they thought that professionals such as social workers and nurses might be helpful, that they acknowledged that this might be the case. The importance placed on the support that might be offered by families was also found by Llewlyn and McConnell (2002) in their study of seventy mothers with a learning disability. This is hardly surprising given the close involvement of families in the individual's lives, the lack of other friends and the often transitory nature of relationships with social workers and community nurses.

The participants suggested a number of forms of support they might benefit from. Participant four thought it would be a good idea to receive parenting classes. He also wished to be shown how to feed and how to give the child any medication it needed. Other types of support that participants thought would be useful included having someone to look after the children if they had to go out, help with the person's own disabilities and on- call support.

3.2.12.e. The context of parenting by men with learning disabilities: Concluding remarks

Although three quarters of the participants expressed the view that they would like to have children at some point in their lives most had limited knowledge about the demands of parenting and the extent of support they might require. Why this is the case was not ascertained and it would be inappropriate to speculate. However, it is likely that the fact that none of them reported receiving any information on parenting may have some bearing on this.

3.2.13. Other's attitudes towards men with learning disabilities having personal and intimate relationships:

This theme is concerned with the way families and others, such as support workers, responded to the participants either experiencing an intimate and personal relationship or expressing the desire for such a relationship.

3.2.13.a. Family attitudes to personal and intimate relationships:

Only two participants (participants two and four) expressed the view that both their family and their partner's family were positive about them experiencing a personal and intimate relationship. Participant seven who did not have such a relationship at the time of interviewing thought his parents would be 'alright' about such a relationship but obviously wasn't able to comment about a potential partner's parents' views.

For the majority of participants, they had mixed responses from families. In some cases as in that of participant five, the participant's family was accepting but the partner's was not. Participant five suggested that this may be due to a combination of factors. Firstly, he perceived the girlfriend's mother as being concerned about her daughter's health. Secondly, he also appeared to accept the common belief that parents are more protective of daughters than sons:

P5, Paras. 295 – 301

Int. *So do you see each other often, or...*

P5 *No, only at work, that's the only time we have contact with each other.*

Int. *Why's that?*

P5 *Because her mother's very strict on what she does and how she portrays her life at the moment with her illness.*

Int. *This is the epilepsy...*

P5 *Yes.*

Int. *Has her mother always been like that or...*

P5 *Yes, 'cause she's a girl her mother, all mothers think of girls / with a boy they think let him get on with it. With a girl they feel more in a protective way for her.*

In other cases, it was the participant's family who were not accepting of the participant being involved in an intimate and personal relationship. For example, whilst participant eleven's girlfriend's family were positive about the relationship his own father was not overly enthused, as discussed in section 3.2.11.a.

However, for participants one, ten and twelve, they only reported negative attitudes from their families. For example, participant one described how his parents were not eager for his girlfriend to visit their house, nor were they willing to take him to visit his girlfriend. As a result of his family's attitude he wished to move out of the family home. Likewise, participant ten's mother did not think he should have girlfriends. However, he was at least able to discuss such things with her whereas his father (deceased) and his grandparents would not even have allowed discussion of such matters. He explained this as being due to them being of a particular generation and over reliant on fiction for their knowledge:

P10, Paras. 177-179;

P10 *...when my father was there he didn't like it 'cause his family are from a different generation. He'd even turn sex documentaries off. Not just turn it off, it'd be 'switch it off now, You're not watching that, I don't care, switch it off now'*

Int. *But your mum's alright?*

P10 *Yeah, I can talk to mam about anything () sexually,*

And:

P10, Paras. 198 - 199;

Int. *Do you think there are any types of sexual activity that are wrong? Some people think...?*

P10 *That's only the older generation that think that. It's because, only because the older generation say one thing and do the other, like I give you an example now, my grandparents say sex is bad, sex is this, only cause they watch bloody dramas, only because they watch make believe dramas like Eastenders and Coronation Street. We're not dramas we're everyday people.*

Although participant twelve's father had not directly stated that he should not have a personal and intimate relationship, he placed considerable restrictions on his son, such as the fact that he was not allowed out in the evenings. His father also appeared to wish to vet any potential girlfriend:

P12, Para. 214;

Int. *Ok. Do you think he'd be happy about you taking her home and her staying over night or...?*

P12 *I did ask him. He said it depends what she's like and how she is and things like that. He said he'll have to see her and then he'll let me know.*

Int. *So he wants to meet her first and see what he thinks about her before he says she can come round?*

P12 *Yeah.*

And:

P12, Paras. 342 – 345;

P12 *He won't even let me go outside the house at the moment. The only time he'll let me go outside the house is on the farm or with my cousins.*

Int. *So do you think that is going to make it difficult having a relationship?*

P12 *Yeah.*

Int. *Um. Do you think that if he meets a girlfriend he'll come round or do you think he'll still be...?*

P12 *My cousin thinks he's starting to come round, but uh, I need to sort things out with him.*

Given such a mixture of expressed attitudes, it is not possible to make a definitive statement on family members' attitudes to men with learning disabilities experiencing personal and intimate relationships. However, the very fact that their attitudes are multifarious does suggest that the participants' families are more positive about such relationships than the family members referred to in the studies discussed in section 1.5.6. Whilst no definitive reason can be given for this difference it is possibly due to the fact that the British studies discussed in that section are at least five years old and legislation, even if not attitudes of the general public, concerning sexuality have changed in this time. For example, the age of consent for homosexual acts was lowered to sixteen and section 28 of the Local Government Act 1988 was repealed during this period.

3.2.13.b. Support workers and other non family member's attitudes to participants experiencing a personal and intimate relationship:

Participants described support workers in statutory services as generally being negative towards the idea of them having relationships. For example, participants three, five and ten said that the staff in the day centre were not happy about service users having relationships. Participant ten suggested this was due to most of the support workers being in their 50s and 60s and posited the view that socio-sexual education workers should visit the centres on a regular basis to talk to staff and service users. Only participant two felt that day centre staff were 'alright' about him having a girlfriend.

Similarly, participant eleven describes how some staff at the college he and his girlfriend attended objected to them holding hands in the corridor. However, a senior staff member was more tolerant as is demonstrated in the following excerpt from the interview with participant eleven:

P11, Paras. 223 – 225;

P11 *Only time people try to stop us, is at college, A was at college at the time as well, the care workers there, cause we was holding hands or cwtching*[31] *each other. They told us it's inappropriate to do it in the canteen. An' we were walking down the corridor holding hands and they said you're not supposed to be holding hands in the corridor. Me and A looked at each other and said what's wrong with it, people often do it. They said if you want to walk to class together you'll have to stop holding hands.*

Int. *Right. Did they say why?*

P11 *No, they just said stop holding hands, but we told them straight, "look we are walking to class it's not wrong". We got into trouble 'cause they said we'll take it further. They took it to the head and the head said "look" to the person who took us there, "holding hands is nothing as long as they're not kissing and cuddling, cause otherwise people get sick of seeing it".*

This finding does not appear to support the findings of the studies of employed carers discussed in section 1.5.5., namely that staff attitudes towards the expression of sexuality by people with learning disabilities are more positive than

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[31] 'Cwtching' is a word used in South Wales with a similar meaning to 'cuddle' or 'hug'.

was previously the case. It is not possible to provide a definitive reason for this difference. However, it may relate to the fact that a number of the studies referred to in the literature review were undertaken with staff who were attending courses relating to sexuality and might therefore be inclined to hold more positive views towards the expression of sexuality by women and men with learning disabilities (Hingsburger 1993; Hogg, Campbell et al. 2001). Additionally, it may reflect a difference in cultural attitudes as none of the studies in section 1.5.5. were undertaken in Wales.

Some participants attending one of the organisations from which participants were recruited (participants one and ten) said that the voluntary staff there were positive about them having relationships.

It is harder to ascertain the views of non-statutory residential support workers as only participant five lived in such accommodation. He stated that his carers had stated that if he desired a sexual relationship this would be acceptable as long as sexual activities took place in the privacy of his bedroom. However, participant four whose girlfriend lived in supported accommodation described her support staff as being obstructive in so far as they rarely allowed him to visit her and would not allow her to visit him. However, whether this was predominantly due to them disapproving of the two of them having a relationship or whether it was more a concern with staffing levels and a perceived inability to provide support for them is unclear as both are suggested by participant four.

Only two participants commented on the view of members of the public towards them having relationships. Participant ten reported that locals in his village commented negatively on the relationship and reported things back to his mother. This may have been in an attempt to show concern for his well-being:

P10, Paras. 296 – 298;

P10 *Yeah, and the public didn't give her a chance.*

Int. *In what way?*

P10 *How can I put this, I've never been on a bender, because I don't like going on a bender, but people in the village would tell my Mam () I think the less people know about you in the city or the town or village the better.*

Participant eleven suggested that although people in his girlfriend's locality were not hostile towards their relationship some people in the area in which he lived had been unpleasant. However, as is described in the following excerpt from his interview, he developed a mechanism for coping with this:

P11, Paras 216 – 219;

Int. *Ok. So what do other people think about you having a girlfriend, do they think that's good or are they worried about things?*

P11 *Well around P (*seaside location where his girlfriend resides*), people know us and if I'm not there they go, 'where's you boyfriend' and that, but round here (*his home town*) they all take the mickey out of us. 'Oh, look at her', or 'she's too young' and one or two of the boys round here called me a paedophile cause she's short, they think she's a twelve year old. I went to the police station and told them I was being called a paedophile and they said what do you mean and I told them, I took my girlfriend with me an all. They asked me what her date of birth is. She came up on the police records and they said, that's ok. Just don't take no notice of them. So fair play, I ignore them now. ()*

Int. *So that's round here?*

P11 *Yeah, in P (*seaside location where his girlfriend resides*) people like me.*

Despite the fact that only two participants discussed the attitudes or behaviour of the public towards participants having relationships, there is no reason to dismiss these findings given that they are mixed as were those of the studies discussed in section 1.5.2.

3.2.13.c. Other's attitudes towards men with learning disabilities having personal and intimate relationships: Concluding remarks

Overall, one is presented with a somewhat mixed picture as to the view of others in relation to the participants experiencing personal and intimate relationships.

This finding is not dissimilar to those of other studies. For example, Davies and Jenkins (1997), in their study of sixty 18 to 20 year olds with learning disabilities, noted that a number of parents of the young people in their sample sought to dissuade their sons and daughters from the idea of marriage and parenting. Likewise, they reported that services such as day centres restricted the opportunities for people with learning disabilities in relationships to be together. Murray and Minnes (1994), on the other hand, found that, in contrast to earlier studies, the staff in their study generally held moderately liberal attitudes. However, this did not necessarily mean that they allowed, yet alone facilitated such relationships. For as Pamela Block (2002) notes, despite a growth in the frequency and openness with which discussion of sexuality takes place, "*...professionals who spoke progressively often acted repressively.*" (Block 2002, p.85). She also reported that parents acted in repressive ways in an attempt to prevent their adult children engaging in sexual relationships.

Likewise in their review of the literature on attitudes towards sexuality, sterilisation and parenting rights of people with a learning disability, Aunos and Feldman (2002) describe mixed attitudes towards this issue. They note that overall, special education teachers and university students hold more positive attitudes towards the expression of sexuality by people with learning disabilities than do parents and service workers.

3.2.14. Participants experiences of bullying and abuse:

This final, short, theme is concerned with the experiences of bullying and abuse that some participants discussed. Five of the participants reported having been bullied or verbally abused as a result of their disability. In the case of participant ten this was in a youth club he had previously attended and he attributed it to the fact that he wore continence pads. He was also teased by people in the village who imitated the way he grasped objects:

P10, Para 107;

P10 *The other thing I dislike about my body is that I pick up a cup with my forehands, I have to pick up a cup like that, (*demonstrates that he picks up cups with the back of his hands*) like my friends are supportive in the village but sometimes they will pick up a cup like me and it gets me down.*

In the case of participants eight and nine they were teased or bullied at school. Such bullying occurred in both mainstream and 'special' schools. Participant seven was teased by a group of females in a public house which he reported had an adverse effect on his confidence. Participant two reported that some of the staff at the fast food establishment in which he worked bullied him.

The support which participants reported receiving over such bullying appeared limited. Although participant eight's mother made complaints to his school and finally removed him from the residential unit attached to the school, participant nine did not appear to have received any support in coping with the bullying. Rather, his father simply took him out of schooling. Participant ten's mother responded in a similar way to the bullying he was experiencing and simply stopped him attending the youth club. Participant two coped with the bullying he was receiving at work by threatening to report the relevant staff to the manager. However, whether the manager would have been supportive of him is unknown.

3.2.14.a. *Experience perceived as sexual abuse and the support given.*

Participant five is the only person who describes an experience which he perceived as abusive. He relayed the experience as follows:

<u>P5, Paras. 145 – 149;</u>

P5 *Well, I'm living with this boy and, um, a few weeks ago, um, I was drunk, I got drunk over Christmas and I was sexually assaulted. I asked for his help and you know, to help me downstairs into the bedroom which in hand then I ended up going to his room. I thought if I can stay with you for the night. I was in his trust, you know and I thought Yeah help me and he said stay with me for the night, if you're bad then we can, I'll help you. I felt really comfortable being there. I didn't feel afraid or intimidated, um, and I was drunk at the time, I didn't know what was happening around me and, um, so, what happened from there I ended up in bed with him which I didn't understand fully what was going on and, um, he had, I woke up in the morning and thought I was in my room and he was next to me. It was really creepy and really scary, and I asked him then when I got up in the morning / He asked me if I was alright and I said yes I think so, and I asked him if through the night he had touched me in any way and he said no, and he had a smile on his face as if to say I know a secret that you don't know, and I asked him full on in front of me did he touch me in any way and he admitted then, in the evening, he admitted that he assaulted me.*

Int. *He just touched you or did he do anything more?*

P5 *He, I think he said he touched me and, um, he said he done something else but he was so drunk he don't remember doing it.*

Int. *So you were both drunk?*

P5 *Yea*

Whether or not the actions would be construed as abuse or not by a court are unclear, given that both men have a learning disability and participant five describes the 'abuser' as '*more disabled*' and '*lower graded*' than himself, the fact that both men also had their ability to make decisions impaired by their consumption of alcohol and the fact that participant five appears to have initiated the occurrence. Although a court may have difficulty in construing the occurrence as abuse, such factors are irrelevant in relation to the support he should have received from his support workers and social worker. However, it would appear that Adult Protection policies were not followed and that his social worker was not supportive. That is to say when participant five reported the events that had occurred to his social worker the social worker told participant five that he should have informed him sooner, as discussed in section 3.2.11.f.

Participant five did state that his social worker phoned around in an attempt to find alternative accommodation. However the social worker was unsuccessful but was unsuccessful in this endeavour. The only support participant five appears to have received from his social worker is a contact number for the Samaritans:
P5, Para. 173.

P5 *I have talked to the social worker and they've given me a number at home for the Samaritans but I don't want to bother with them. I just want to get on and just live my life like any other day.*

3.2.14.b. Participants experiences of bullying and abuse: Concluding Remarks

Situations such as that described above are no doubt difficult to resolve and one acknowledges the finite resources available to Social Services and other organisations. However, it is alarming that no Adult Protection Policies appear to have been in place or, if in existence, were not followed particularly, given that

Social Services are supposed to take the lead in such matters (National Assembly for Wales 2000).

Part four: Concluding remarks and Recommendations:

4.1. Introduction:

The study was small scale and of men belonging to self-advocacy type organisations who lived in South Wales. Moreover, neither women nor men with a learning disability are a homogenous group, as may sometimes be thought to be the case when they are spoken of as '*people* with learning disabilities'. Likewise, there is no 'one' experience of sexuality for men. This is demonstrated in this study by the fact that findings in relation to specific issues varied. Rather, there exists a diverse range of sexualities (Daniluk 1998). The study can not, therefore, provide a single or unified model of men with learning disability's understanding of and experiences of sexuality issues.

However, the study demonstrated that although heterogeneous, the men shared a number of things in common with one another. This finding is similar to those concerned with the experience of women with learning disabilities (e.g. Dorney 1999; McCarthy 1999). Additionally, the men in the study shared some commonalities with non-learning disabled men. Given this, the findings may be useful for suggesting further, participatory research that results in liberation rather than oppression (Cocks and Cockram 1995). They may also be useful for suggesting changes in the policies and practice of those organisations and individuals that seek to support men with learning disabilities in their daily lives. This final part of the dissertation seeks to make some such recommendations. The following recommendations are not in order of priority, but in the order they arose in the study:

4.2. Choice, autonomy and adulthood:

It is clear from the findings of this study that despite over thirty years of normalisation / social role valorisation, and the promotion of 'quality of life', and despite participants demonstrating that they were capable of making and expressing meaningful choices these choices continue to be restricted in relation to many aspects of their lives. This was the case whether participants lived with family members or in group homes. Such aspects included not only matters relating to the expression of their sexuality but also such basic things as their accommodation, occupation, and finances. These findings are, therefore, similar to those discussed earlier at section 1.6.2. They also echo those of Owen (2001) and those of Stalker and Harris (1998) who reported their research into the exercise of choice six years ago. Whilst it is generally accepted that the ability to make choices is influenced by factors such as communicative ability, cognition, previous experience, and staff beliefs, people can be taught choice making skills. Given that choice making has considerable advantages for men and women with a learning disability and there are few, if any, reported detrimental aspects to this (Stalker and Harris 1998), it is important that choice is encouraged. That there is a need for service providers and carers of women and men with learning disabilities to work in a manner that assists people in becoming more confident and competent in decision making has been recognised for considerable time (Sands and Kozleski 1994). However, it requires professionals and others to move from a paternalistic approach which is dependency inducing to one where clients and carers are working in alliance with one another (Brechin and Swain 1988).

The men in the study appeared not to enjoy many of the rights, status, opportunities and such things as are generally seen to signify a move from childhood to adulthood. That is to say they had neither autonomy nor independence. Additionally most did not have physical and/or emotional separation from their parents. Although there is currently a trend amongst the general population for people to leave home later than has previously been the case (Jordan and Dunlap 2001) many of the men in this study expressed a wish to leave. However, they also expressed the view that it was unlikely to happen in the near future.

Although advocacy and self-advocacy movements may have resulted in improved autonomy and control for some individuals, not all individuals with a learning disability are able to self-advocate or access an independent advocate. Even if they do, there is no guarantee that the man or woman with the learning disability will have *their* voice heard and responded to. There is a need for a change in the perception of professional and non-professional carers from that of a provider of services to that of a facilitator who works in conjunction with men and women with learning disabilities and enables them to plan and achieve their goals. Additionally, greater resources need to be made available in order that women and men with learning disabilities are able to access independent inexpensive advice. Whilst there is already such a need, it is likely that this need will increase if the Mental Capacity Bill introduced to Parliament on the 17th June 2004 becomes law (Wheeler 2003).

4.2.1. Summary of recommendations for practice:

- Service providers and carers need to work in a manner that assists men with learning disabilities to become more confident and competent in decision making. This requires a move from a paternalistic, dependency inducing approach to one of facilitation where carers and clients work in alliance with one another.
- There is a need for greater resources to be made available for independent inexpensive advice, such as advocacy services.

4.2.2. Summary of recommendations for policy change:

- When new legislation and policy is introduced, care must be taken to ensure adequate funding is available to meet needs resulting from such changes. For example, the Mental Capacity Bill, if enacted, will increase the need for access to advocacy services.

4.3. Economics; Occupation and finances:

A further issue that has arisen in this and previous studies, as discussed at sections 1.6.2.; 3.2.2. and 3.2.3. is the issue of economics. In relation to this issue two main suggestions were discussed in the literature. Firstly, that society expresses a negative attitude towards men and women with learning disabilities expressing their sexuality due to a belief that people with learning disabilities are non-productive and are a net drain on the economy. Secondly that men and women with learning disabilities do not have sufficient funds to access and participate in community activities where they might meet potential friends and lovers. The current study provided a somewhat mixed picture of others' attitudes to men with learning disabilities experiencing personal and intimate relationships and parenting as discussed in sections 3.2.12. and 3.2.13. However, it clearly found that most of the participants had little money and little control over that money. As a result of this most of them were unable to afford to participate in activities amongst the local community.

It appears to me that in order to ameliorate this situation, policy makers have two main choices. Firstly, greater emphasis could be placed on supporting men and women with learning disabilities in employment. As Walmsley (1991a) noted over a decade ago there is a need to provide opportunities for employment for women and men with learning disabilities as their seeming failure to contribute economically to society undermines any claims they make for citizenship and equal rights. This view was echoed by Trent (1995) who argued that unless people with learning disabilities have jobs they will have only an illusion of equality with the majority population. This may be even more so for men than women given the 'traditional view' of the male as 'breadwinner'. Moreover, as discussed earlier at section 3.2.2., employment would also offer additional advantages to men with learning disabilities.

Men with learning disabilities are likely to be at a disadvantage in the labour market due, amongst other things, to a lack of key skills that may be sought by employers. Although some of the men were receiving training in information technology, such training did not appear to be provided with a view to increasing participants' chances in the labour market. Rather, it appeared simply to be a means of occupying the men. I would argue that there is a clear need for services to provide training that increases men with learning disabilities chances of obtaining employment in what is generally considered a post-industrial society (Riddell, Baron et al. 2001). Additionally, the benefits trap would have to be addressed in order that those men with learning disabilities who obtain employment are not financially penalised for so doing.

A second alternative is for society to provide higher state benefits and for expansion of direct payments schemes. Whilst this may not have the same benefits as promoting employment, it may negate the problems arising from a lack of money and may also result in men having greater control over the services they receive.

4.3.1. Summary of recommendations for practice:

- Services should provide training that increases the chances of men with learning disabilities obtaining employment.

4.3.2. Summary of recommendations for policy change:

- Greater emphasis should be placed on supporting men with learning disabilities in employment than is currently the situation.
- The current 'benefits trap' and regulations relating to 'therapeutic employment' needs reviewing and addressing in order that men with learning disabilities gain a financial advantage from employment. Alternatively, higher state benefits should be provided and there should be a simplification and expansion of the direct payments scheme.

4.4. Community Participation and Inclusion:

The current study suggests that despite the fact that most men with learning disabilities live in the community rather than in long stay institutions it remains the case that many men with learning disabilities are not truly participating or included in their local communities. One result of this is that the men have reduced opportunities for meeting potential friends and partners. Although the men in the study did not explicitly express the view that they were lonely, the lives they described appeared to be quite isolated and lacking in friendships. The significance of relationships within our lives cannot be understated, in so far as we are all interdependent, both needing one another and wishing to feel needed (Llewellyn and McConnell 2002). Social support is seen to act as a buffer against social stigma and stresses caused by such things as life transitions (Llewellyn and McConnell 2002) and, as discussed earlier, (section 3.2.5.) there is a need for increased social support in order to address such issues. Although there is a need for relationships with non–learning disabled individuals, relationships with peers and staff are important and should not be undermined by those pre-occupied with 'social role valorisation'.

Whilst there are numerous possible reasons for the fact that men are not truly participating in their communities, as discussed previously (section 3.2.4.), one reason may be an excessive concern with risk and possible litigation. Whilst services obviously do need to be aware of risk and act to reduce it, it must be remembered that a major aim of services is to promote autonomy and independence. Rather than preventing people from participating in community activities because of a concern that their doing so may place the individual or society at risk, they should seek to support the person in doing so appropriately and safely. Policies relating to risk assessment should recognise and explicitly refer to this in an attempt to reduce unnecessary control over the lives of men and women with learning disabilities.

4.4.1. Summary of recommendations for practice:

- Services should provide men with learning disabilities with increased support in accessing and participating in their communities.

4.4.2. Summary of recommendations for policy change:

- Policies relating to risk assessment should emphasise the appropriateness of supporting men with learning disabilities to express their sexuality in an appropriate and safe way rather than preventing them from expressing their sexuality.

4.5. Body image and sense of self:

The findings of this study support the view of Shakespeare et al (1996) that body image is an issue of concern for people with both physical and learning disabilities. They are also similar to the findings of McCarthy (1999) in her research with women with a learning disability. She found that most of the women in her study felt it difficult to describe positive features about their bodies. Moreover, ten of the fourteen participants wished to lose weight and were perceived to have been affected by social pressures to achieve a particular body shape and size. The findings of the current study do, however, appear contrary to the findings of Ogden (1992), namely that men's body-image does not affect their self-image to the same extent as women's body-image affects their self-image. However, this may be due to her research being concerned with men without learning disabilities or physical disabilities. This is due to it being probable that men with learning disabilities have low self-esteem which is seen to be a factor in negative body-image in men as discussed at section 3.2.6.d. Whilst it is necessary to conduct further research on this issue, it would not be inappropriate for concurrent work to be undertaken with men with a learning disability with a view to increasing their self-esteem and body-image. For example, cognitive behaviour therapy (CBT)has been used successfully with women and men with learning disabilities in relation to a variety of issues (Kroese, Dagnan et al. 1997) and may be of value in improving self-concept and quality of relationships. One example of its use in this field is provided by McGaw, (2002) who used it in an attempt to improve the self-concept of a group of parents with learning disabilities. However, although the participants' self-concept improved after the CBT, it is not clear whether the CBT affected the positive change or whether it was due to the 'feel-good factor' arising from group attendance (McGaw, Ball et al. 2002; Murphy and Feldman 2002).

In order to challenge societal views of men with learning disabilities being passive, dependent and helpless and thus 'less than real men' (Shakespeare, Gillespie-Sells. et al. 1996), we are presented with a conundrum. On the one hand, we could promote independence and autonomy amongst men with learning disabilities in order to challenge the notion that they are somehow not 'real' men. However, to do so, whilst possibly improving the way in which men with a learning disability are perceived by the majority population, it may further encourage people to view women as lacking, what are seen as, positive masculine characteristics and thus encourage different treatment of women to heterosexual white males. An alternative approach would be to promote independence and autonomy amongst men with learning disabilities whilst at the same time challenging the notions of the 'ideal' male in an attempt to reduce the inequalities between men and women.

4.5.1. Summary of recommendations for practice:

- Services should work to improve the self-esteem and body-image of men with learning disabilities, for example by using cognitive behavioural therapies, and addressing power imbalances between carers and their clients.
- Services should work to promote independence and autonomy in men with learning disabilities whilst at the same time challenging notions of the 'ideal male'

4.5.2. Summary of recommendations for further research

- Research should be conducted into the relationship between low self-esteem and negative body-image and ways of addressing such a relationship.

4.6. Understanding of others through being male:

Whether the way that the men in the study understood others and difference such as women generally, women with learning disabilities specifically, lesbian relationships and homosexual relationships differs greatly to that of the majority population is unclear and further research in this area would be of interest. However, the findings do suggest that anti-discriminative legislation is not effective in promoting either perceived or actual equality between heterosexual men and; lesbians, homosexual males, disabled persons and women generally[32]. Services should ensure that they have policies in place that recognise diversity and promote equality. They should ensure that these are accessible to staff and service users and that both receive appropriate training on these issues. They should further ensure that sexism, homophobia and racism are addressed in a manner that not only sends a clear message to the perpetrator but also ensures that the person so discriminated against receives appropriate support.

4.6.1. Summary of recommendations for practice:

- Services should ensure they have policies in place that recognise diversity and promote equality. These should be accessible to staff and service users and appropriate training should be provided on these issues.
- Services should ensure that discrimination is addressed in a manner that both clearly signals its unacceptability and which ensures that the person discriminated against receives appropriate support.

4.6.2. Summary of recommendations for policy change:

- Policies should recognise diversity and promote equality. Such policies need to exist at both national and local levels.

4.6.3. Summary of recommendations for further research

- Further research should be conducted into the way that men with learning disabilities understand others and difference, whether this differs greatly to the majority population and how such attitudes might be improved.

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[32] The study did not include questions relating to ethnicity. This was not an oversight, rather it was a result of the fact that the organisations from which the men were recruited did not have members from minority ethnic communities.

4.7. Socio-sexual education:

Socio-sexual education is a further area of concern. Some of the concerns raised by this study have previously been recognised in the literature (see section 1.6.). Both the extant literature and this study suggest that socio-sexual education for women and men with learning disabilities tends to concentrate on biological issues which emphasise the negative aspects of sexuality. Men with learning disabilities appear to be being discouraged from sexual expression because of concerns about risk (to themselves and others) rather than being told that it can be pleasurable. Socio-sexual education should include greater discussion of the reasons why one might engage in sexual activity, the fact that it should be a pleasurable experience for both parties and that it may present minimal risk.

Additionally, there is a need for socio-sexual education to discuss emotional aspects in relationships rather than concentrating on the bio-physical aspects of sexuality. There are currently few published programmes specifically concerning relationships and women and men with learning disabilities. One of the few positive examples to be found is that of Jobling et al (2000). Rather, most programmes are predominantly concerned with such things as, the prevention of abuse, pregnancy and STIs. For example, in *Sex and the 3Rs* (McCarthy and Thompson 1998) there are only two pages specifically given over to the subject of relationships. Similarly, *'Talking together about growing up'* (Scott and Kerr-Edwards 1999) has only one page on the issue of relationships. However, its more recently published companion book, *'Talking together about sex and relationships'* does have a chapter on relationships of various sorts (Kerr-Edwards and Scott 2003).

The current study also suggests that men with learning disabilities are not taught about women's bodies, but only about their own. They appear to place excessive emphasis on penetrative vaginal intercourse but do not appear to be aware of the clitoris and it's purpose. Additionally they do not seem aware of the sexual pleasure that both partners may gain from alternative activities such as massage. These findings are similar to those of McCarthy (1999) who found that half of the participants in her study had only experienced penetrative sexual intercourse. She also found that the women described sexual activity on television as very different to their own experience because it included such things as kissing, cuddling, and remaining in bed with the sexual partner after the sexual act had taken place, things that they had not personally experienced. In order that both men and women with learning disabilities find sexual activity enjoyable, socio-sexual education needs to discuss women's bodies, activities additional to penetrative intercourse, and the fact that sexual activity should be a pleasant activity for both partners.

The present study also found that men had forgotten much of what they had been informed of. As discussed previously, this may be for a variety of reasons. Additionally, some of the information they had retained appeared to be outdated or incorrect. It is important, therefore, that men with learning disabilities receive accurate, appropriate and accessible socio-sexuality education throughout their life-times.

4.7.1. Informal sources of information about socio-sexual issues

It is clear from the findings of this study and that of McCarthy (1999) that both men and women with learning disabilities gain much of their information about sexuality from informal sources such as peers, family members and the television. Whether this information is always accurate and appropriate is not clear, though from my own experience I consider this unlikely.

Like McCarthy (1999), I am of the opinion that peer education or support may be beneficial to men and women with learning disabilities so long as the peer educators have the requisite knowledge, attitudes and skills. I also share her view that peer education or support should be complementary to professional socio-sexual education. However, I do not necessarily agree with her view that this should be the role of male support workers. Whilst one would expect appropriately trained male support workers to have the necessary knowledge, attitudes and ability to undertake this role and to have positive relationships with the men they support, this is not necessarily the case. Additionally, as shown in the findings of the present study some of the information provided to the participants was incorrect or out of date. To give support workers the role of providing socio-sexual education would require that they ensure their knowledge is correct and up to date. Given my experience of staff shortages preventing staff from attending training, I feel that support staff would find keeping their knowledge up to date difficult to say the least. Moreover, it may be more embarrassing or difficult for men with learning disabilities to talk to their support workers about sexuality, than to an independent advisor. This study and those of McCarthy (1999) and Strike (2002) suggest that many men and women with learning disabilities do not feel able to talk to carers about sexuality issues. Moreover, they suggest that support workers and 'professionals' do not appear to be good at listening to women and men with learning disabilities, an issue that requires addressing. The men may also be concerned that their conversations may not be confidential, in so far as they may be unnecessarily discussed by the support worker with other support staff. Given the above, I am of the belief that socio-sexuality education should be carried out by specialist socio-sexual education workers with the support of peer educators and care support workers as appropriate to the individual.

A further concern relating to informal socio-sexual education relates to the fact that the information gained by men and women with learning disabilities from television programmes such as soap operas may not always be accurate, helpful or appropriate. The producers and writers of such programmes should be encouraged to ensure that issues of sexuality are dealt with sensitively and accurately. Additionally, those working on sexuality matters with men and women with learning disabilities will need to ensure they address any false information or unacceptable attitudes such as sexism, racism and homophobia that may be portrayed in popular television programmes.

4.7.2. Summary of recommendations for practice:

- Socio-sexual education should be broader than it generally is at present. It should include such things as discussion of possible reasons why one might engage in sexual activity, emotional aspects of relationships, women's bodies, and activities additional to penetrative intercourse. Whilst there is a need to discuss such things as abuse, pregnancy and sexually transmitted infections, the overall emphasis should not be negatively biased. Rather a balanced view should be presented.
- Rather than emphasising the negative aspects of sexuality, what is needed is that service commissioners, service providers and carers need to be aware of clients' needs in relation to sexuality issues (Cambridge 1996). Having gained such awareness, they should seek to empower people with

learning disabilities in order that they can express their sexuality (Edmonds and Collins 1999).

- Socio-sexual education should accurate and accessible and should be appropriate to the needs of the individual. It should be provided throughout the person's life time.
- Services should provide training for potential peer educators who may provide men with a learning disability with education and support that is complementary to professional socio-sexual education.
- Services should train staff to act as specialists in socio-sexual issues. These staff may then work both with individuals or groups of men with learning disabilities and with staff.
- Staff should be encouraged to address any inaccurate information, or unacceptable attitudes such as racism, sexism and homophobia that may be portrayed in popular television programmes and magazines.

4.7.3. Summary of recommendations for policy change:

- The writers, producers and publishers of television programmes and magazines should be encouraged to deal with issues relating to sexuality in an accurate and sensitive manner. This should reflect appropriate legislation appertaining to sexual behaviour and to anti-discrimination.

4.8. Sexuality and the law:

One reason posited in section 1.6.2. for carers not supporting people with learning disabilities in expressing their sexuality was law. It is clear from the study that a number of the men had misapprehensions about the law, for example, believing that one needed the consent of a potential partner's parents or that sexual intercourse without a prophylactic was an offence. Additionally none appeared to be aware of the offences specifically relating to people with learning disabilities and few appeared to have anything more than a very limited understanding of consent.

Why this was the case is unclear, however, my own experience is that many individuals, including professionals, such as doctors and nurses, do not understand the law relating to consent. This was exemplified in the relatively recent case of Pembrey v The General Medical Council (2003) UKPC 60. Here, a doctor had been struck off the register as a result of having carried out sterilisations on two women with learning disabilities. Although he had the agreement of the mothers he had not properly analysed the capacity of the women he sterilized to consent; he had not sought the opinion of other doctors and he had failed to obtain the leave of the court. The Privy Council dismissed his appeal against being struck off the General Medical Register and once again reminded practitioners of the legal requirements of consent and of the fact that in England and Wales no-one can consent on behalf of someone who has reached the age of 18.

In addition to the problematic issue of consent, the law current at the time of this study being undertaken presented carers with numerous issues which have been discussed in section 1.5.2. and in other literature (e.g. McCarthy 1999; Wheeler 2002). Since this study was undertaken, new legislation, namely The Sexual Offences Act 2003 has come into force[33]. Despite this Act having received considerable discussion in Parliament and having been subject to public consultation, it is far from perfect. For example, the 2003 Act appears to emphasise protection rather than empowerment, it fails to define consent adequately and there are likely to be a number of difficulties with the interpretation of some sections of the Act (Wheeler 2004a). Having said this, however, it does go some way to addressing many of the concerns expressed in relation to the previous law.

Whether men with learning disabilities will have the new law explained to them adequately remains to be seen, though I personally think this unlikely. Currently there is an assumption that everyone is aware of law, that is to say, it is no defence to plead ignorance of the law. Given the amount of legislation produced and amended annually, comprehensive knowledge of the law is unrealistic for any citizen, let alone those who may have cognitive or communicative disabilities. It is important, therefore, that a concerted effort is made to provide men with a learning disability and their carers with accurate information about the new laws in a manner that is accessible and comprehensible. Whether a duty to provide such

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[33] The 2003 Sexual Offences Act came into force on 1st May 2004, commencement order 2004 No. 874 (C.38).

information should lie with statutory services such as social services, health or education or whether it should lie with the legislature is a moot point. However, in order to ensure that the most appropriate information is provided on a national scale, I would recommend that it be produced centrally, either by the Home Office, or another Government department such as the Department of Health.

4.8.1. Summary of recommendations for practice:

- Services should ensure that staff and service users have a knowledge and understanding of the law appertaining to sexual behaviour and issues such as consent.

4.8.2. Summary of recommendations for policy change:

- Central government should provide accessible guidance in relation to legislation appertaining to sexual behaviour and complex issues such as consent.

4.8.3. Summary of recommendations for further research

Research into the working of the 2003 Sexual Offences Act, as it impacts upon women and men with learning disabilities needs undertaking. The results of such research should be used to amend the relevant sections as appropriate.

4.9. The attitudes of others towards men with learning disabilities participating in personal and intimate relationships and parenting:

The findings of this study suggest that it remains the case that many parents and carers of men with learning disabilities have negative attitudes towards them expressing their sexuality and participating in personal and intimate relationships. The extent to which this impacts on the ability of men with learning disabilities to express their sexuality is not wholly clear, although this study suggests that it is substantial.

There is a need for more up to date research across a variety of types of respondent in order to determine the factors that affect people's attitudes towards supporting, or otherwise, the expression of sexuality by men with learning disabilities. Having undertaken such research, one could then undertake work with carers with a view to altering their attitudes so that they become more positive towards the expression of sexuality by men and women with learning disabilities. Most studies suggest that workshops on sexuality or other sexuality training has a positive influence on carers' attitudes towards the expression of sexuality by people with learning disabilities. For example, Brantlinger (1983) found that both group home staff and institutional staff were found to have more liberal attitudes after attending a one-day sexuality workshop. Hogg et al (2001) also found that an open learning course on approaches to the sexual abuse of adults with learning disabilities had a positive effect on the attitudes of those undertaking the course. Other authors who found that sexuality training had a positive influence on carers' attitudes include Rose and Holmes (1991). However, Sebba (1981) reported that that there was little change in people's views or behaviour following a one day workshop, though it did serve to stimulate discussion amongst staff on policy issues. The reported experience of Blakey et al (1996) was similar, in that parents' views on sexual relationships for young people with learning disabilities remained divided even after the parents had attended sexuality workshops (Blakey, Frankland et al. 1996). Likewise, a number of authors such as Heyman and Huckle (1995) and Johnson and Davies (1989) suggest that in relation to staff attitudes towards the expression of sexuality of people with learning disabilities there is a discrepancy between the attitudes expressed by staff and their behaviour. The reasons for such a discrepancy are unclear. However, both Johnson and Davies (1989) and Holmes (1998) suggest that it may be the result of the minority of staff with conservative attitudes being able to exert a disproportionate amount of power over the more liberal majority as a result of the majority feeling inadequately prepared to deal with issues around sexuality.

Given these findings research clearly needs to be undertaken into the extent to which attitudes influence carers support, or otherwise, of such relationships (Aunos and Feldman 2002). Having completed such research, attempts can then be made to address the findings in such a way that parents and carers become more supportive of men with learning disabilities who wish to express their sexuality in a lawful manner.

4.9.1. Eugenics, and the 'New Genetics':

As discussed earlier in sections 1.3. and 1.6.2., one of the main causes of the supervision, sterilisation and segregation of people with learning disabilities was the influence of the eugenics movement. Whilst the movement lost its acceptability and much of its following after the Second World War, it remains the case that it is lawful to abort a foetus with a disability at a later stage of pregnancy than one without disabilities and pre-natal screening services are widely available. Not only are they available, but their use is encouraged and seen as routine (Alderson 2001).

Recently, there has been a resurgence of interest in the topic of pre-natal screening and the prevention of disability as a result of work done on the human genome (Kevles 1995). Although most forms of learning disability do not have a genetic cause, some clearly do (Watson 1997). Examples include Down's syndrome, Turner syndrome, Fragile X syndrome and Cornelia de Lange syndrome. Whilst testing for Down's syndrome has been available for many years, the number of genetic tests available has increased dramatically in recent years (Fletcher 2001). However, whilst testing has advanced, treatments have not, with the result that very few conditions once diagnosed can be treated (Chadwick 2001).

Despite the existence of the United Nations Universal Declaration on the Human Genome and Human Rights (Rothman 2000), which aims to set ethical standards in relation to the use ethics, a number of writers have raised concerns about 'new genetics', in particular about the issue of testing. Genetic testing raises a number of ethical issues (Antonak, Mulick et al. 1995). One such issue is the question of why undertake testing. The results of a test may be used for positive reasons, such as in order that parents can receive advice on how to prepare to care for a disabled child or in order for service providers to allocate resources (Chadwick 2001). However, the information may be used for more negative reasons such as to decide who should have children (Nemeth and Johnson 1995). Although in England and Wales, unlike China, there is no legal requirement that foetuses with a disability should be aborted, there may be considerable pressures exerted on women carrying a disabled foetus to have an abortion (Kuna 2001). Moreover, many people believe that people with disabilities should not have children (Waxman 1994).

There is a need for this and numerous similar issues to be openly debated on a national scale in order to ensure that genetic technology is not used to discriminate against or prevent disability, difference and diversity (Rioux 2001).

4.9.2. Summary of recommendations for practice:

- There should be greater inclusion of sexuality in the content of syllabi of those training to become professional carers such as nurses and social workers.
- Services should provide greater support to formal and informal carers as to how they might better respond to the sexuality of those they care for.
- Services should ensure they have up to date policies on the subject of personal relationships which facilitate lawful sexual expression by service users. Staff should be made aware of these policies. They should also be advised of the fact that preventing men and women with learning disabilities form expressing their sexuality may result in disciplinary or legal action where this is a breech of the employee's duty of care.

4.9.3. Summary of recommendations for policy change:

- There is need for a nationwide open debate about the use of genetic testing and its implications for men with a learning disability. Clear policy guidance should be provided in respect of such testing.

4.9.4. Summary of recommendations for further research

- Research should be conducted across a variety of types of respondent in order to determine factors that affect people's attitudes towards supporting, or otherwise, the expression of sexuality by men with learning disabilities.
- Research should be undertaken to ascertain the extent to which attitudes influence carers support or otherwise of the expression of sexuality by men with learning disabilities.

4.10. Bullying and abuse:

Although ascertaining whether men with learning disabilities were subject to bullying and abuse was not intended as part of the study, it became clear that a number of the men had been subject to bullying as a result of their having a learning or physical disability and that one participant perceived himself to have been sexually abused. The support which most of the participants received who had been bullied or abused was minimal. There is an urgent need to address such issues both at a policy level and practical level. In relation to policy there should be both national and local policies outlining the unacceptability of bullying, ways in which it may be prevented and responses which should be taken if it occurs. These could be in a similar vein to the adult protection policies produced by the Welsh Assembly Government (2000) or the Department of Health (2000).

At a practical level, such policies need to be accessible to both carers and men and women with learning disabilities and they need to be used. Service providers should also seek to address the power imbalance between service users and carers. For example they could promote an atmosphere of mutual respect whereby carers work in partnership with men and women with learning disabilities and the imposition of carers' views upon service users is strongly discouraged.

4.10.1. Summary of recommendations for practice:

- Services should ensure that policies relating to bullying or abuse are accessible and that they are implemented.

4.10.2. Summary of recommendations for policy change:

- National and local policies should be produced concerning the issue of bullying, methods of prevention and appropriate responses.

4.11. Concluding remarks:

It has been said that, "*...interpretative research is about finding out what it is that makes us different, or indeed the same*" (Williams 2003: p.70). Whilst I recognise the limitations of this study, such as its size, the method of sampling and the fact that all participants were recruited from similar organisations in one locality, I sought to adhere to this principle and believe that the results do have wider implications for policy, practice and research.

Despite there having been some considerable changes in the treatment of men with learning disabilities during the last thirty years, in relation to their being supported in the expression of their sexuality, change has been minimal and painstakingly slow (Kaeser 1992; McCarthy 1999). Men with learning disabilities still appear to be denied adult social roles in the areas of paid work, control over finances, and personal and intimate relationships, a finding reported some 13 years ago by Walmsley (1991) and 18 years ago by Flynn and Saleem (1986). It is hoped that the recommendations I suggest will be considered and implemented by a variety of individuals and organisations including partnership boards, service commissioners and providers, advocacy groups and those supporting self-advocates. This would be in an attempt to benefit men with learning disabilities wherever they may reside.

Paul Wheeler
September 2004.

Part 5, Appendices:

5.1. Appendix One: Draft Topic Guide (as presented to the Tizard Ethics Committee)

The subject areas below are simply a guide. Questions will not be put to participants in the way they are formatted / worded here. Rather, the focus groups and interviews with men will be largely unstructured in order that the men have control over what they tell me rather than them being restricted by a structured interview.

Details about age, employment, where they live, etc.

Opportunities of meeting people/making friends, e.g;
What places do you go where you meet people?
When you go there can you talk to people you don't know?
Can you give people your phone number / contact details?
If you need someone to support you when you go out do you choose where and when you go or is it up to the person supporting you?
Do you have enough money to go out and meet people?
Can you stay out late or do you have to be home at a certain time?
Can you bring friends home?
Is there somewhere you can be on your own without people coming in?

Self perceptions:
Do you think you are different to other men?
What do you like about your body, e.g., shape, weight, health, looks, etc?
What don't you like about your body?
Is there anything you would like to change about your body?
Do you think you are attractive?
What do you think makes someone attractive?
Is there anything you would like to change about yourself?
How could you change this?
What do you think other people think about you?

Knowledge and attitudes about sexuality issues, e.g;
Have you ever had any form of sexuality education?
Can you tell me what it was about?
Who gave you this?
Did it include information on: (a) physiological aspects e.g. the body, puberty, pregnancy and child birth; (b) consent; (c) sex and interpersonal relationships (d) STIs / sexual health; (e) law; Etc.
What does sex mean to you?
Do you think sex is OK?
Are some types of sexual activity wrong?
Do you think carers think it is ok for you to have sexual relationships?
Would you like more information about sexual things?
If you haven't had sexuality education, where did you learn what you know about sexuality / sexual relationships?
Do you think sex can be dangerous?

Do you know where you can get condoms from?
What do you think about pornography?
Have you seen pornography?
Do you use pornography as a sexual stimulus?
Do you think women with learning disabilities are the same as women without learning disabilities?

Intimate relationships:
Do you have special friends like a girlfriend or boyfriend?
Would you like a girlfriend / boyfriend?
If you have a girlfriend / boyfriend how did you meet them?
If you have a girlfriend / boyfriend how long have you been in the relationship?
If you have a girlfriend / boyfriend what sort of things do you do together, e.g. go for walks; go to the pictures, etc?
What does 'love' mean to you?
What is different about your girlfriend / boyfriend and your other friends?
What is important about your girlfriend / boyfriend, e.g. sharing, nice to be with, help you when you need help, looks, the way they touch you, etc
If you have a girlfriend/ boyfriend are you able to have time together on your own?
Is your relationship with them physical, i.e. do you do sexual acts together, e.g. kissing, massage, mutual masturbation, oral sex, penetrative sex, etc.
If your relationship is sexual, how does it make you feel, e.g. do you both enjoy it?
What do other people think about you having a girlfriend/boyfriend?
How do carers react to you having a girlfriend / boyfriend e.g. do they help, for example by making sure that you have privacy or do they disapprove, for example by stopping you meeting this person?
Would you go out with a girlfriend / boyfriend with learning difficulties?

Hopes for the future:
If you have a girlfriend / boyfriend what sort of things would you like to be able to do e.g. be able to sleep together, live together, get married, have children, etc.
Do you think this is possible?
If not why not?
What sort of support would you like from your carer / service provider?
If you don't have a girlfriend / boyfriend would you like one?
If yes, do you think you this will happen?

5.2. Appendix Two: Transcripts of the four interviews transcribed initially using a bottom up approach. Namely, those of participants, two, five, eight and ten.

NB: When imported to NVivo, the lines and paragraphs become automatically numbered.
Names of places and people have been removed in an attempt to protect their anonymity.

5.2.1. Transcript of interview with Participant Two

P There you are, do you just want to say how old you are, and something about yourself while we check that this is working? Can you do that for me?
P2 38
P Right, and um, do you live in M or B?
P2 M
P Well that seems to be working alright. That's good because the other week it didn't work properly. Ok, um, So... Are you warm enough?
P2 Yeah, I'll warm up
P So, what do you do during the week do you work or?
P2 Yes, I do work down Mc Donaghs.
P McDonalds? What do you do there?
P2 Cleaning for the boss
P Do you enjoy that?
P2 Yes
P Do they pay you well?
P2 They pay me, yeah
P That's good. How long have you been working there?
P2 About, phh..., 3 years.
P Three years, that's a fairly good length of time isn't it? Has it always been the same boss there or...?
P2 Yes, while I work there, yeah
P Ok. So, um, do you live at home or do you have your own house or...
P2 Down my sisters
P You live with your sister. Right. Have you always, have you lived with your sister for long or...
P2 Yes, alright.
P She's ok is she? She looks after you?
P2 Yeah
P Ok. The first questions I would like to ask you are about what opportunities you have to meet people and make friends. So do you want to tell me what sort of places you go to where you can meet people? I know you come here. Where else do you go to meet people, to make friends?
P2 Um... like down the centre in B.
P Do you go anywhere else to meet people?
P2 No
P Do you go to pubs?
P2 Yeah
P Um, what sort of pubs do you go to, local ones, or ...
P2 Yeah
P Do you go to pubs in B as well?
P2 B, Ah
P What about C?
P2 Yeah
P Do you go there very often?
P2 Yeah
P What days do you go to the pub?
P2 Uh... Thursday
P So who do you go with, friends, mum and dad?
P2 Friends

P Ok. When you go there do you meet people you don't know? Do you meet new people or do you always just talk to the same people?
P2 Ah, the same people all the time, uh,
P Ok, so do you ever meet new people there?
P2 Yeah, (unclear) there
P Do you go and sit with them or do you just sit with your friends?
P2 I talk with them, aye.
P Are you on the phone?
P2 No, my father
P your father's on the phone
P2 yeah.
P Do you have a mobile phone at all?
P2 My father does
P So if you met someone you liked and you wanted to arrange to meet them again would you give them a phone number or address or what would you do?
P2 Phone number.
P Ok. That would be okay would it? Your father wouldn't complain about that?
P2 No.
P Right, that's okay. So when you go out do you go on your own, or how do you get there?
P2 Uh ...there's..., with my friends
P Do you catch the bus or does someone drive you there or?
P2 No, staff from there, in the centre take us
P Staff from the centre take you
P2 They take us.
P Right, what about, you know you said you go out on a Thursday, to the pub, is that in the evening or in the day?
P2 In the day
P And staff take you. Do you go out to the pub evenings at all?
P2 No.
P No. Do you stay in in the evenings then?
P2 Yes, I stays in on the settee all time.
P I see, so do you ever go out in the evenings?
P2 No
P If you go out, say like today you've come out. How do you travel? Does you dad bring you or ...
P2 I walk.
P You walk. So if you fancied going somewhere else, I don't know, if you fancied going to the pictures or something, how would you get there?
P2 Uh ... there ... sometimes I go down the rugby club watching rugby up the se(unclear)s
P There's a match on this afternoon isn't there?
P2 Yes up the se(unclear)s for the match. There the best
P So you were saying you don't go out at night very often. Do you ever go out at night?
P2 No
P No? What if you wanted to, would that be ok?
P2 I like stay in
P You don't like going out?
P2 Not allowed to just stay in all the time
P Do you think, um, some people say that they don't have enough money to go out because they're living on benefits or whatever. Do you get benefits as well as money from McDonalds?
P2 I get some money, yeah
P Is that enough money for you?
P2 Yeah, ... twenty pounds is a great day, a lot for work (unclear) It's like, do, like, down McDonalds what ever your doing, right coming in the kitchen you take the, uh, chips box an' lift it up, right, an tip the box, take the lid off, rip up the blue bag, tip 'em all in and they went in and there's a big lot of room and they do all the cooking and I said I'm fed up of that, right, an one girl who pulled my arm again I will report him. He's cheeky with me, do that an' do that. I'm fed up I can't be allowed in the kitchen. Say I'm not doing the toilet anymore. I'm not paid for it, any more hassle I'm going to your boss, the manager and I said why don't you come down the kitchen don't be in your office and sit down at all, get up of your fat arse and do some real work, dusting. I said (unclear) man with glasses on I'll tell him you cant be allowed to, I phone up and like report you an all that (unclear) and me if I phone up, right I will report her. I say you in your office (unclear) why you pulled my arm, you bruised my arm, your fault, I say enough about your work grabbing me like that I'm here to help you back (unclear). I said I've had enough, you've bruised my arm, your abusing me, you'll be sacked. I can, I will report you and you'll be sacked. (unclear)
P What happened
P2 We had a new boy, my friend, like me, ain't it. (unclear) They decided to sack him. They gave him a check and told him to go and he went. He'd had enough

P He went did he?
P2 He went didn't he. He wasn't getting enough and they were picking on him. My cousin
P Did they pick on him because he had a learning disability?
P2 They're all right with me. He had enough of them picking on him
P It's not nice when people pick on other people is it?
P2 Like my cousin. He's all right, but they pick on him all the time
P You are talking about work. Do you think they pay you the same as everyone else?
P2 Yeah
P So it's fair money is it?
P2 Yeah, money, yeah
P So you can afford to go out if you want?
P2 I can afford to go out ... yeah
P So do you go out on your own to the pictures, or swimming or something like that?
P2 Me not go swimming any more
P You don't go swimming any more
P2 My father takes me down Bridgend, Friday for food, buy things, check computer, computer
P You've got your own computer have you?
P2 Yeah
P Okay so you have enough money to go out if you want to
P2 Yeah to buy things, an that
P That's good to have enough money. If you wanted to go out in the evening, you say you lived with your sister, would she mind if you went out or would she be worried?
P2 She wouldn't mind
P So what about, do you take friends home? Is that ok
P2 Yeah
P Is that friends who are men or do you bring girlfriends home, or...
P2 My missis
P So you have a girlfriend then?
P2 ...
P Right. So how long have you been going out with her then?
P2 About 11 years.
P That's a long time isn't it?
P2 Be 11 years now, long now. Wedding in a couple of months
P So you are getting married?
P2 ...
P Are you engaged?
P2 Engaged, yeah
P So, did you buy each other anything for an engagement present?
P2 Yes, uh, like buy her a rings an uh
P That's nice. So where did you meet your girlfriend?
P2 In the centre
P In the centre?
P2
P It's a long time to go out with someone, 11 years. So you're engaged, so what does her family think about that?
P2 Oh, they're alright
P Alright?
P2 Yeah, her mother and her father are ok. My missis will have a baby an she went bad for three days I phoned up and said come up the house, she's ok now. My missis wants me to work all the time.
(Knock on door, interruption by Mike giving me a list of men interested in participating in the study)
P2 Yeah they're alright
(goes back to talking about the day centre and another client picked on his girlfriend by kicking her – he asked the staff to take the client's boots from him)
P You know you've been going out with your girlfriend for about 11 years what sort of things do you do together? Do you go...
P2 Like shopping, the two of us go shopping and a cup of coffee
P So do you do that very often?
P2 Yes. The two of us go out with staff
P Every day, every week?
P2 Monday, Friday
P A couple of times a week then?
P2 Yes, we ask the staff if we have money and ask them to go to town and shop and buy things
P Sneezed

P2 I tell them we will be back in about ten minutes and we have a coffee and tea, and coke. Then we look around the shops and buy things and we are back about ten past three and then we walk back into the centre

P Do you go out to the pictures together or go out for a meal?

P2 Just shopping an that

P So when you go out together you mainly go shopping

P2 And for a cup of coffee and tea an that

P You know the centre, what do the staff at the centre think about you having a girlfriend? Are they ok about it or do they think you shouldn't have ...

P2 Yeah, they're alright.

P They're alright are they. That's good. You said that her family is ok about it, what about your family?

P2 They're alright with the two of us going shopping. When my missis comes down they take us shopping and that.

P So you take your missis home sometimes?

R2 Yes

P And does she ever stay overnight?

P2 Yes. Her mum and dad let her now. At the weekend now at my sister's house, sleep in my bed, see

P So they're alright about you sleeping together as well?

P2 Yeah.

P If you don't want to answer this, that's fine, but do you have any sort of sexual relationship?

P2 No

P You're not?

P2 No

P Ok. Is that because you don't want to until you are married or?

P2 Not long till we get married. She's having a baby I'll be a father soon.

P So she's pregnant now is she?

P2 Yes

P Are you both managing with the pregnancy alright or ... ?

P2 Yea, yes, alright.

P What did people say when they found out your missis was pregnant?

P2 They were alright. She's happy

P And you're happy?

P2 Yea

P So are you looking forward to having children?

P2 I only want one boy

P You want one boy do you?

P2 One, One boy now, I'll feed him and change him, like in a pram and take him walks and let him sleep. I'll be alright and we'll be moving now to me own, a house on our own.

P So you're moving out?

P2 To live on our own, see

P So when's that...

P2 My missis can come and live with me, see. We can sort things out like.

P That will be good. Do you think you will need any help with bringing the child up or do you think you can manage, just the two of you?

P2 We'll manage

P Do you think your sister and people will help you?

R2 It'll be ok, uh, my sister can come down my house, see, it's ok, like, like my sister will bring some cakes down

P That's nice that she does some cooking for you

P2 And a bottle of wine. It's ok a bottle of wine and cakes down and she'll have tea with us and dinner at my house, see.

P So, was having a baby something you wanted, something you planned or was it an accident

P2 No it wasn't planned. Its I wait now till Saturday, next week and then we'll go down the church and back the house and sit down and, uh, have a bottle of wine and watch the telly and sought things out now, do, uh, painting the house now.

P So you've already got the house and you're decorating it

P2 It's my father's renting it. It's a hundred pound my house. The kitchen there we'll have space. My father 'll do it, the papering. He's doing it now, the ceiling, scrape the wall down first, then do the ceiling, see

P So is your missis helping you do this or are you doing it on your own?

P2 My missis is cleaning out the back see

P You've been going out all this time, so, has your family always been ok about you having a girlfriend?

P2 Yeah

P That's good. So they're quite positive are they?

P2 Yea

P So do you just want the one child or do you want more?

P2 One, one child

P One's enough is it?

P2 Yes

P Do you think you'll know how to bring the child up or do you think you'll need people to help you?

P2 We'll manage

P That's good. So you love your girlfriend do you?

P2 Yeah

P So can you tell me what love means to you? So if you love your girlfriend what does that mean?

P2 Uh, I love her and she loves me. (unclear) We like going to P, we like the bumper cars, sweets, key rings, toys an all that.

P So, can I ask you, for you to be having a child you had sex together?

P2 Yeah

P Do you have sex together a lot?

P2 Quite a lot

P And you both enjoy it?

P2 ...

P Right, that's good. You said that your family are quite positive and helpful. And her family, are they ok about it?

P2 Yeah

P Ok. There are some other questions I need to ask about how you feel about your own body and how you feel about how you look. One of the things is do you think you look different to other men or do you feel different to other men. You know sometimes you get magazines like 'Men's Health' and you see men doing body building and stuff. Are you happy with your body, do you go down the gym?

P2 I go down the gym

P How often do you do that?

P2 Oh, a lot.

P How many times a week?

P2 uh, about four times a week

P That's quite a bit isn't it. You said you hurt your foot playing football. How often do you play football?

P2 Oh, um, a lot

P Every week,

P2 Every week, yeah.

P What day was it you played, yesterday?

P2 No Wednesday

P Wednesday you played?

P2 I hurt my foot. On the side its paining me, my toe, on the side

P You'll have to go and see the doctor

P2 Yeah

P See what they can do.

P2 My dad put some stuff on it

P A spray?

P2 A special one. I wear special shoes one of them catches all the time and I don't want a bad foot all the time. I had a plaster on before. My foot better next week.

P I hope it gets better soon.

P2 It'll be better when I get new special shoes see. I've had em checked out see.

P Right. You said you like going to the gym. Is that because you like doing exercise or is it because you want your body to look muscular and...

P2 Yeah it is

P Do you want to look like the people in the mag...?

P2 Yeah

P So you know some people have plastic surgery, face lifts and things is there anything you would like to change about your body?

P2 Change my body, just change it.

P What would you like to change about it?

P2 My shoulders, back and front

P You'd like to have more muscles?

P2 Yes

P Well I guess the thing to do is keep going down to the gym isn't it. So, do you, obviously your girlfriend thinks you're good looking doesn't she

P2 Yeah

P So if you think about yourself and how you see other men such as on television do you think you're the same as other men or... Different?
P2 Yeah
P Which?
P2 Differnet, see. My missis sit down my missis go and she sit down you see.
P What do you think it is that makes someone attractive to someone else? What is it that makes you want to go out with someone?
P2 Um, if I did that my misis would dump me, she'd walk out so I keep my mouth shut. It's ok then see.
P Do you think other people think you're attractive? Do other women say you're good looking?
P2 Yeah, yeah. I'm alright.
P Right, so you're happy about your body but would like to have more muscles. There's nothing else you'd like to change?
P2 No
P The last lo of questions I'd like to ask you about are around sex education. Do you know if you ever had any sex education?
P2 No, its like my missis ain't bothered, she isn't always wanting sex, she's not bothered.
P So at school or in the centre
(he talks about painting and how it makes his arms ache)
P has anyone talked to you about puberty, pregnancy birth or anything like that
P2 No
P No one has ever gone over good things and bad things about relationships and stuff like that with you
P2 No, keep it, like talking about it, you can't have to keep your mouth shut about it.
P Has anyone talked to you about staying healthy sexually and stuff like that?
P2 Sex is alright as long as you keep your mouth shut, keep your mouth shut, keep it to yourself.
P So if no-one has talked to you about sex and things, how did you learn about sex with your girlfriend? Did you see it somewhere, did you read it?
P2 Ah, we seen it for ourselves. It's up to us if we do it. People fucking do it but you keep it to yourself.
P Do you think sometimes sex can be dangerous?
P2 No
P Have you ever heard of things like infections or HIV or AIDS?
P2 No
P You know you said you only wanted one boy. How are you going to make sure you don't have any more children?
P2 No, one's enough
P So how are you going to stop having any more?
P2 We stop having more babies
P How do you stop having more babies?
P2 I don't want any more, one's enough
P So do you know how to stop having more babies? Do you use a condom?
P2 I've got to wear it, like men's and women's.
P Men can have an operation to stop them having more babies, women can as well and women can take tablets to stop them having babies. Do you use condoms?
P2 Yeah, they're alright then we chuck them straight tin the bin when we've finished
P You were saying you are looking forward to getting married. Do you think that some things are men's things to do and some things are women's or
P2 We share jobs
P Are there some things that you think your missis should do or will you both do the same things
P2 My missis she likes doing shopping, she'll check the money and things
P She's good with money is she?
P2 She can count money. When we buy things at the till she checks the money
P Good. So who will do the cooking when you are living together?
P2 (points to self)
P You're a good cook?
P2 I always cook see
P What about cleaning, are you going to do it all, or are you going to share it?
P2 We'll share it ok. My missis wants to sit down, I'll make her a cup of coffee.
P That's nice. Will she cook for you sometimes?
P2 Yeah
P can she cook alright, is she a good cook
P2 (shakes head)
P You're better?
P2 Um, I tell her to sit down

P Does she have a job as well or does she just go to the centre?
P2 um, yeah she works with me
P Where does she work, in Macdonalds?
P2 In the centre.
P I hope it all works out for you. Hopefully everything will be alright but if you did need help where would you go to? Say your boy is ill who would you ask for help?
P2 um, call an ambulance
P I see. One last thing that I haven't asked you. Do you know what I mean when I say pornography?
P2 pornography?
P Like 'dirty magazines', films
P2 Oh them yeah
P Do you ever look at them?
P2 I have.
P I just wondered if you ever bought them or looked at them and what you thought about them
P2 I look at them, see, there's nothing wrong with that if you put them away.
P Ok. Does your missis look at them as well?
P2 Yeah we both look at them
P What does she think about them?
P2 They're alright.
P Well there is nothing else I want to ask you is there anything you want to ask me?
P2 No
P No, okay. Thank you very much, that's for helping me with the interview (passing him £5.00)
P2 Thank you

End of interview
Duration 51 min 17s

5.2.2. Transcript of interview with participant five

(71:09 min)

P Right can you just say a little bit about yourself so I can check this is working properly?
P5 Right, My name is D, um, I've come from M. I've lived in a couple of places, um first of all I lived in M, um in W Street in M. Then I moved to L, I live with my parents there for nearly eight years and then I moved to C. That's where I live at the moment on my own and I live with another partner.
P Right
P5 It's just me and him
P And you share the house?
P5 We share the house
P Ok. Could you tell me how old you are?
P5 I'm 42
P 42, Ok. And do you work at all or...
P5 No, I go to, um, well I've worked in a few places. I've worked in Somerfield in M, I've worked in an animal sanctuary, looking after animals and sick animals. I've worked in, what is it, a nursery for plants and things like that.
P And do you work now, or...
P5 Yes, I work at 'CC' in M
P Is that every day or...
P5 Five days a week
P And do you get paid for that?
P5 Yes I get paid
P There are different sorts of things I want to ask about. The first thing I want to ask questions about is what sort of opportunities you have to meet people, like friends and that.
P5 Well, um, well I go out every other Friday with my friends who I know from here, from PF. I have been asked to go out with E down to a club called F which I haven't had the opportunity yet because of social, um, apprehensions have stopped me now, like my parents. They feel that I would be taken advantage of
P Right, so what's F, or where is it?
P5 It's a club, a night club in M.
P Right, but you said you think that your parents think you might be taken advantage of
P5 Yes, I, I'm one of these people who can be, um, very vulnerable to shall we say like ungood people, people who are / I used to go around and get in a lot of trouble once with gangs of groups of people which

were unworthy to my family's eyes, you know. I've learned from that. I thought, you know () I've got in a lot of trouble with people like doing, uh, stuff like, glue sniffing and things like that

P Ok, so you go out once a week...

P5 Once a week, once every other week to a night club and things like that

P So when you go there do you tend to stick with the people that you know or do you talk to new people

P5 Perhaps when we go there we all mingle together first

P Right

P5 We have a laugh and a joke, you know, like you do in it, then we talk about different things un, um, and then perhaps have a few dances together and see if we can click onto somebody, you know. But other than that we just stand by the bar and drink all night

P Fair enough. So...

P5 And talk about the day's events

P So do you meet many new people when you're out or do you mainly stick with the people you know?

P5 I mainly stick with the people/ um sometimes I stay with my friends and sometimes if I know someone I go and chat to them

P Ok. Say you meet someone that you haven't met before

P5 Right

P And you think, 'they're quite nice, I'd like to meet them again' what would you do, would you give them your phone number, arrange to meet again, what sort of things

P5 Perhaps I would give them my phone number, I'm terrible. I'm one of these people who like to give phone numbers out to any body, um, and I like to get to know/ I either like to approach them with a subtle excuse, 'would you like to come back to my place?' or 'would you like to get in touch with me again?'

P Right. So you'd feel happy about giving them your phone number

P5 Oh, yes, I would feel happy as long as they were honest abiding people and they wouldn't use the phone number for any other methods

P Ok. How would you know that? Is it just something you would feel, that they are ok, or...

P5 No, I would ask first about their variations on abiding person understanding each other's trust, um, and if they feel / If I feel comfortable that they are an honest abiding person and they wouldn't spread my number around the community I would be happy about it

P Right. You're a very able person and you live with another person. Does the other person have a learning disability?

P5 Yes, he's got a lower standard of disability than me. I'm much higher graded than this other person is

P Ok. Do you have support workers there or... ?

P5 We have carers coming in each morning and evening.

P So they wouldn't stop you going out if you wanted to?

P5 No, if I wanted to go out as long as I tell them where I was going and what time I would be coming back, there's no / if you want to go out they say, 'if you want to go to the pub, you go'

P Right, but you would tell them where you were going?

P5 Where I was going, yeah. Say I was going to B for the day, I'd say right then / they'd give me a stated time and if I got my mobile with me I'd say I'll be back at a certain length of time

P Ok. Would anything be said if you weren't back on time?

P5 If I weren't back on time, um, they would start ringing round to see where I was, or look for me

P Why do you think that is? Is it because they are worried about you or...

P5 It's part of general practice with them, to safeguard their backs, you know. As long as they know where I am or who I'm with then they're happy

P That's fine. So you don't need anyone to support you when you go out?

P5 No. I go out everywhere, around the place. I go around the country on my own

P Ok. You said that you work?

P5 Yeah

P Do you / one of the things some people have said is that they don't have enough money to go out and meet people and do the things they'd like to do. How do you feel about your money?

P5 My money. I get my money in, um, a small percentage each week, enough to cover me for the week, you know

P Right. So what sort of amount of money do you get a week?

P5 I get about £10 per week pocket money

P Right. So do your benefits go straight to the place that is providing the accommodation?

P5 No my benefits go to / I get my social benefits and it goes to my mother and she sees to all my finances

P So she pays your rent and everything?

P5 Yeah

P Ok. So you've got about £10 per week to spend.

P5 I get £10 a week

P Do you think that's enough or do you think you should get more or...

P5 Well, with age I've asked for a few things / with my age I've asked if I can have my pocket money upgraded, like a normal person would have enough money to cover them, you know, enough money to see them through for the week or forthcoming time.

P So all your food is bought is it?

P5 No, we do our own shopping

P Right

P5 The staff take us down to do our shopping

P Ok

P5 And we pay bills with them and things like that

P So you only get ten pounds a week to spend on yourself

P5 Ten pounds, yes

P You said that you can stay out late if you want, there's no problem with that. What about taking people back. Say you meet someone you like and you wanted to take them back would that be all right?

P5 Well, they said yes, they sat down with us and said anything that you've got on your mind, anything you want to talk about, they either take us to the side to another room or / I've asked them if it's alright, if I bring other people back to the home and they said yes. A young lad came. His name is ID. He came to my house the week before last and he had / well I asked him if he wanted a cup of tea. He's in to gaming like me. He's one of these people that like play station games and things like that and he came back / but the odd thing about him, he's like one of these fanatical people who is on about religious sets and he came there and the odd thing about it and I would be straight with you, first of all he sat on my bed and said 'what have you got to show me?' I said, relax and be mellow and I'll show you. He said 'Oh, I've had a busy day, stressed out today' I said 'oh have you, what's been going on then?' 'Well he said, I'm not clicked with myself' I said what do you mean by 'not clicked with yourself''. He said I'm not spiritually, um, clicked with the spirit side of the world.' I thought, oh no, what road are we going down by 'ere and he said to me, 'Well, I'm not. I don't know if I'm spiritually with God or I'm spiritually with myself.' I said 'have you talked to people about it?' and he said 'Yes, I have talked to people, but I'm not satisfied with myself.' And I said, 'well, you know, you want to go out there and talk to other people about it, um.' And he said / next minute then apart from that he said 'Oh, I'm so tired is it alright if I close my eyes for five minutes' I thought, 'close your eyes in my room.' He lay back on my bed, so I said, 'I've got the game on by here now' and he said 'I'm so tired is it alright if I close my eyes for five?' And he just lay on my bed and I was on the floor then, um, I said 'look I've got the game on now I, if you're tired wouldn't it be best if you want to go home?' And he said 'Well, um, I should think about doing something like that, but I don't want to be on my own, I need to be with somebody at this time' And, um so I said 'the game is on' and started playing my game. He said 'Is it alright if I lay on the floor?' I looked at myself I thought 'Oh my God what is going to happen now' He got off my bed and laid on the floor, um, and he said 'I've got to close my eyes for five' and I said what's wrong then I and he said 'I'm just not, I'm trying to communicate, you know, I blame God for, I don't know if I blame God for what he's done or I blame myself for my Gran's death' I thought, Oh, he's going off a rave here. So I said to him 'I, its best if you / if you're tired butt I'd go home if I was you.

P Did he?

P5 Yes, I thought it was real weird and spooky for someone to / you invite someone into your home and they act in that strange manner

P May be he thought you were a friend who...

P5 I am a friend, yeah

P may be he thought you'd be ok about it?

P5 Um, but if you invite someone into your home you don't expect that

P No

P5 You expect them to sit and talk or interact with each other. You don't expect them to play the full 'ogg' in front of you, you know and / that was weird, in my eyes that was really weird

P But you handled it well?

P5 I did. After that I went / I thought I'm not having him here again. I told the members of staff and they said he can come and see you in work but he's not to come to the home again

P Yes. If you meet someone / you can bring friends back so that's not a problem. What about if you found a girlfriend or boyfriend and you wanted to bring them back?

P5 Well, I have got a girlfriend, um, but we're / it's like a tutonic friendship

P Platonic?

P5 Yes, it's not like very, um, a full on type relationship type of thing.

P So does she come back to your place?

P5 No, I've, um at the moment she suffers with epilepsy and it's hard for her to live a normal life with her condition so her Mother tends to mollycoddle her and keep her in

P Oh. If she wanted to come round to your place and her mother was Ok about it would your carers be ok about it?

P5 Yes they said if I brought my girlfriend back or a friend I know, 'cause I've had loads of friends in my life girls and boys, you know, they say yes, it's your house you do what you want

P Ok. So, I presume you've got your own bed room

P5 Yes

P So if you have a friend in there, whoever it might be, is it private or do you get interruptions

P5 It is private. If the staff come down, they say are you all right, are you comfortable, then they say carry on then and let us to get on with whatever we are up to or doing.

P Right. The next lot of things I want to ask about are how you see yourself, whether that be physical aspects of yourself or how attractive you think you are. They're the sort of things I'd like to talk about now

P5 Um.

P So do you think you're different to other men or the same as other men or...

P5 Well, I like to think of myself as / I've always been a very positive person, a very structured upgrading person in society. A lot of people know me and a lot of people, um, outside the family I'm well known, a likeable character, um, () up for anything you know

P uh, huh

P5 um, that's the sort of person I see myself, outgoing, ambitious, um do anything with any body you know and just try to enjoy my life the best way I know how.

P So do you think most men have similar attitudes about that sort of thing?

P5 Well different men have different ways of thinking haven't they?

P Yes

P5 Some people think straight on about life other people have got different ways of going through it.

P Ok. You see other men go to work, go home, have careers, have families, that sort of thing. Do you think that makes them any different?

P5 No I see a normal structured man would have that, these responsibilities in life, like going to, getting up in the morning, seeing to his family, seeing to his wife, you know making sure his wife is ok and things like that and having that normal circle of life within the family

P Ok. Some people have things about their bodies they don't like. So for example if I had the money I might get laser treatment so I wouldn't have to wear glasses

P5 Ok

P So the next question is: are there things about your body that you like, are there things you really like about your body

P5 Well I feel about my body, I feel about my body, I feel I'd like to improve my body structure, more muscles, um, my physique. I'd like to have a better physique than what I got now 'cause when you go out with the boys or my friends they are butch and have got muscles, not muscle bound but they turn round and say D you're the only puny one in (unclear). I said yes that's just me, the way I like to be. I'm not the type of person who would like to be muscle bound and I can pull the women, or anybody the way I am. It's not how you look it's how you act in front of people, how you portray yourself

P Right. So if you could change anything would you

P5 Yes, I've always wanted a sex change

P Right

P5 I've always thought, being a man, I'd like to experience the female side of life

P Right

P5 But that will never happen in a million years, so I've got to live the way I am.

P Why do you say that will never happen in a million years?

P5 You've got to have money for these type of things and you've got to, you know, know the right people and the right connections and things like that.

P So, I guess the other thing is it would be permanent as well, so you couldn't...

P5 Yes, you couldn't come back to the way you were, but, um, I've always felt myself personally to be, when I was younger, I used to think I was like a girl, like I had girl's feelings and things like that. I always thought I was a girl, that was in my younger years. That was my experience and feelings and emotions.

P Do you feel that way now? Do you feel that you are a woman trapped in a man's body sort of thing, or?

P5 Years ago I did, I had, I always thought I acted like a girl, a girl's emotions, a girl's physical being, but, um, and that was just my, I asked people, I was talking to people and they said that's just your body telling you you're going through body experiences, that was my teenage years and I was going through ()

P Puberty?

P5 Yeah

P People's bodies do change as you go through puberty and there are hormones released which may cause you to have different emotions, so it could be that, but you don't feel that way now?

P5 No, I feel that, I'm, um, a normal person with normal attitudes. If I wanted to change my sexuality I would, um, I did once before, long time ago, thought that I was going to turn, lesbian or gayish, where it was hard for me to think about which side of the sexual trinity I wanted to be and I couldn't talk to nobody about it, um, I had to investigate myself, um, was I going to be straight or was I going to be the other way and I wondered about myself and thought if I had a chance and could have had both sides I would like to experience the both sides of life, cause there is nothing stopping anybody being what they want to be and how they perform their life. It's how you feel inside that's most important

P You said that, um, you didn't feel that you could talk to anyone about that?

P5 No, if I went that way, beside, it's everybody's choice, if they want to be gay that's up to them, um if wanted to I think I would lose a lot of friends and my family bondage and that's what frightens me about that.

P Ok. Is that because you think that they don't think it's right, or...

P5 They think it's odd, it's not right, you know, it shouldn't be in society and I feel it's to their own personal best, you know, everybody

P Yes

P5 it should be each to their own, if you want to lead that type of life it should be up to you

P So do you still feel that you'd like to try both ways or...

P5 Well, I'm living with this boy and, um, a few weeks ago, um, I was drunk, I got drunk over Christmas and I was sexually assaulted. I asked for his help and you know, to help me downstairs into the bedroom which in hand then I ended up going to his room. I thought if I can stay with you for the night. I was in his trust, you know and I thought Yeah help me and he said stay with me for the night, if you're bad then we can, I'll help you. I felt really comfortable being there. I didn't feel afraid or intimidated, um, and I was drunk at the time, I didn't know what was happening around me and, um, so, what happened from there I ended up in bed with him which I didn't understand fully what was going on and, um, he had, I woke up in the morning and thought I was in my room and he was next to me. It was really creepy and really scary, and I asked him then when I got up in the morning / He asked me if I was alright and I said yes I think so, and I asked him if through the night he had touched me in any way and he said no, and he had a smile on his face as if to say I know a secret that you don't know, and I asked him full on in front of me did he touch me n any way and he admitted then, in the evening, he admitted that he assaulted me.

P He just touched you or did he do anything more?

P5 He, I think he said he touched me and, um, he said he done something else but he was so drunk he don't remember doing it.

P So you were both drunk?

P5 Yea

P Are you ok about that or?

P5 I've been really upset, feeling disgusted about it. I have been feeling dirty and emoralised. I was at his trust and that really / I have broke down and cried about it. I haven't told my family because I would feel that I would loose my family

P So you feel disgusted to some extent. Do you feel angry with him, or... ?

P5 I feel really angry with him. I asked him about it, you know confronted him to his face and he turned round and said, well you asked to come back to my room, but I said I was in your trust and this is how you take my trust, taking advantage of someone who was immobilised at the time and you've done wrong in my eyes. He said no, he says, you wanted to come to my room, so we went from there.

P Do you feel like you want to take it further?

P5 I have asked been to take it further but my family doesn't want me to get involved, get the authorities involved like the police and things like that.

P Your family doesn't want you to

P5 No

P But do you want to?

P5 I would love to take it further but, um, within the contents of that, I don't want to rock the boat on both sides, like if his family found out he would be, they would be quite alarmed for what have happened.

P Given what's happened how do you feel about living in the same place as him?

P5 Yea, I do feel frightened and unsure of myself. I make sure now that he gives me my own space. It creeps me out being in the same house with him, you know. If I had somewhere else to go I would move tomorrow but there is nothing in the social service structure.

P Have you spoken to your social worker about it?

P5 Yes and he's gone really dea / he is off and really feels that if two people agree, if it was an agreeable thing, then he wouldn't have taken it so bad, but he said it wasn't agreeable, I didn't agree to the, what happened, he feels disgusted on the trust there was no stopping at the time.

P So, is he going to do anything about it, is he going to find you somewhere else to live, or...

P5 No. They asked, on the day it happened, they did phone around to see because they reckoned I was unsafe or no, unsafe being there and they wanted to find me somewhere for the night you know, but they phoned round and there was nothing for me so I had to stay in the house with the perpetrator.

P Ok () Given that you have disclosed this to me, you've told me about it, is there anything you want me to do about it, do you think you would like me to contact your social worker about it or...

P5 Um, no, I think its best be left under the carpet now

P It's entirely up to you. If you want me to do something about it, I could, but it's up to you.

P5 But its, it was over Christmas when it happened and like my social worker said, you should have said something in the beginning so we could have done something about it, but now its been left, and only now you're speaking out about it. But like I told him, I've been finding it really hard to speak out.

P I can understand that

P5 You know I didn't know who to turn to, I was on the brink of suicide over it, because I felt so dirty and so um () so dirty and so lonely and so vulnerable after it, and um, I've just lived every day on the belief that things could get better with our relationship there.

P There are helplines for people who've been raped and things like that. It might be worth getting in touch with them and you could talk things through with them.

P5 I have talked to the social worker and they've given me a number at home for the Samaritans but I don't want to bother with them. I just want to get on and just live my life like any other day.

P What I will say is you've got my phone number there. If at some point you do want to do something about it, or you do want information about helplines or anything just give me a ring and I'll find some information for you that would be confidential.

P5 Ok, I've, I've talked to people and I've gone over it in my own mind how I feel and its like, um, like someone invading your space without your consent and it's not right in the modern world.

P No people should always consent and never have anything forced upon them

P5 No, it was, um, if I had consented to have gay sex, I would be agreeable, but I haven't. I've never been that kind of person, and if I did agree to it, then it would have been on both parties, it would have been agreeable, but it wasn't, it was straightforward sexual assault.

P Well I'm very sorry about that, but you say you're dealing with it the way you want...

P5 I'm dealing with it the way I want.

P Ok () So we were talking about attrãction to / how attractive your body was and you were talking before about how your friends were muscly and things like that, and you also said that you did think at one time you'd like a sex change. So thinking about now, is there anything you'd like to change about your body now?

P5 Um, my appearance, to be more prettier

P What do you mean? Don't you think you are pretty, don't you think you are attractive?

P5 No, I don't think I'm good looking at all. Everybody says I am, you know my mother says I'm a good looking lad but I don't think I am. If I had a chance to change my whole appearance and my body I would

P So () how would you like to look?

P5 Um, more, more, butcher, and more, um, attractive to the opposite sex.

P I'm trying to think what you might like to look like. You know film stars...

P5 Jean Claude-Van Damm

P That's who you'd like to look like?

P5 Yes, Jean Claude-Van Damm

P Right, now I've got some idea of what you would like to look like. So you don't think yourself very attractive but other people do. What is it about someone that makes a person attractive? What do you think makes a person attractive?

P5 What makes them attractive is the way they are groomed, the way they are dressed, and the way they look

P So the way they look, the way they are groomed and the way they dress

P5 Yes

P Ok, you said you'd like to look like Jean-Claude Van Dam

P5 Yes, I've got a poster of him on my wall in my bedroom.

P Right, Is there anything you think that you could do to make yourself look more like that?

P5 Go to the gym, workout

P Ok, Do you do that?

P5 I used to, I used to a lot once. I used to be a really fit fanatic. I still do go swimming every Friday, and I take multi-vitamins now everyday, but I'd like to be much more, I'd like to be more creative about myself. That's the proper word to put into text. I'd like to be more creative about my body, more positive in myself

P Ok, fine. You said your mum thinks you're attractive. What about other people, do they say you...

P5 Well, no, my girlfriend thinks, well I haven't asked her feelings, you know, I have done a lot of things with my girlfriend which is appealing to her and she says she likes me for the way I am, and she wouldn't want me to be any other way and I thought well wouldn't you want me to be more meaner, leaner, and she says no I like you just the way you are that's you ain't it.

P Ok. The next questions are about what you know and what your attitudes are towards sexuality issues, so again if there is something you don't feel comfortable about talking about, that's fine, just say...

P5 Ok.

P One of the first things I'd like to know is have you ever had any form of sex education at all?

P5 In school

P Right. Can you remember what it was about?

P5 It's about the birds and bees and like, um, about what happens when a man and a woman goes together and things like that

P Fine, so I guess they talked about things like how your body changes as you get older?

P5 Yes

P Pregnancy?

P5 pregnancy, they talked about the pill, they talked about condoms, and the safety of condoms, and, um, the diseases you can pick up from sexual int()

P Intercourse?

P5 Intercourse, yes.

P Did they talk about positive things about relationships?

P5 Yes, one of the positive things they talked about was, um, when two people meet and they understand each other's feelings, um, and they build a relationship and it goes from being a relationship to something sexual

P Yes () Do you think you had enough sex education or do you think they should have told you more or...

P5 I know more, I know enough anyway.

P Have you learned more since, from other places, or...

P5 No, I watch it on TV

P Ok, what sort of things on TV

P5 I watch the porn channels, where you can pick up extracts. I write it down, I've got a notepad I write it down and think Oh that's a good idea, that's a good position or something

P Right, so have you got satellite?

P5 Yeah

P Do you have to pay extra for that?

P5 Five, only done it once, that's all you pay £5.99. Once you've paid it once you can watch it as long as you want.

P I see. So did your sex education talk about consent as well?

P5 Yes. It talked about that in school, we had a sex education officer come in and he showed us some slides on different things and he told us you've got to have consent, you can't just go doing sex without consent.

P Ok. The word sex, it means lots of things to different people

P5 Um

P Could you tell me what it means to you?

P5 Sex means like, male or female, um, it can mean behaviour like sexual intercourse

P Yes it can mean different gender, like a man and a woman and it can refer to behaviours. Thinking about sexual behaviours do you think that all forms of sexual behaviour are ok or are some...

P5 Some sexual behaviour can be formed behind closed doors as long as it's in the right manner. You wouldn't do something in public or to make the public eye aware, you know, you do what ever you do behind closed doors

P Ok. Do you think that some kinds of sexual activity, or sexual behaviour as you said, are wrong?

P5 Yes, I think its wrong, like, um, bondage, people in bondage, I think that's wrong where they are tying people up, but that's everybody's way in it? I can't say you can't do that because it's wrong

P The law does say that some types of sexual activity are wrong, but do you think any other types of sexual behaviour are wrong?

P5 Lesbian sex

P You think that's wrong

P5 Yes

P Why's that?

P5 I think it's disgusting having two women performing a sexual act with each other, knowing that they are both females.

P Ok. What about two men, is that ok?

P5 I think if two men were compatible and they knew each other well, I'm all go for gay relationships and gay sex and I think it's a free world it's how people want to be. You can't say it's wrong for two men, cause, you find that sort of thing in college. There were two boys in school when I were there and they were a bonding relationship and they were walking around arm in arm and I thought, you know, nothing wrong with it. Years ago people used to demoralise it and they did think it shouldn't be allowed. But now it's past the millennium, turn of the century and people live their lives the way they want to.

P Right, but you think that if you had a gay relationship you'd loose some of your friends?

P5 I would loose a lot of friends. If I did turn gay, that would be up to me, you know at the end of the day it's my life. If I wanted to go the other way I would, you know, but, you've got to understand the morals of the relationship, which way it's going to go, you know.

P You said your carers are ok about you having a girlfriend back or whatever. Do you think they would be ok about you having a sexual relationship with your girlfriend?

P5 Yes, I asked them the other night about it. They said if you want to have sex in the bedroom, you know, with the door shut we wouldn't say anything.

P Ok. You also said you had sex education, but you've also learned some stuff from the television. Do you think you've learned more from the television and other people or more from school?

P5 I've learned more about each other in my own personal relationships with my girlfriend. The stuff we have done, you know, that brings us closer to each other.

P Ok. Do you think that sometimes sex can be dangerous at all?

P5 Yes, some sorts of sex could be dangerous

P Could you say what sort of / how it could be dangerous

P5 Um, not using a condom, um, you can go with somebody who has got a disease and you wouldn't know anything about it and you would catch that disease.

P That's true. So if you had sexual intercourse with somebody what sort of precautions would you take?

P5 I won't ever wear condoms, I don't like them

P You don't?

P5 No I'm one of these free, antichrist people I think. God give you an actual function to use and why use something that's not, you know. If the girl's on the pill that's alright. I've slept with loads of girls and I always ask before I proceed with any sort of sex, are you on the pill and they go yes. I've got to take their word for it.

P What about / you said that some people could have infections. One of the things about condoms is they can stop you getting infections, so you'd never think of using a condom?

P5 I'd never use a condom, um, I used it once, I used a condom once and it just made my stomach bloat, um and I had pain in my groin when I was using it so I don't use one.

P Okay. Pornography, you've said you've seen some – what did you think about it?

P5 Well I thought, you know, it's alright for a laugh to watch on telly, you know, if there is nothing else on telly I would like watching x rated

P What sort of pornography have you watched – men and women, men and men, women and women?

P5 Yes I watched both sides of it I watched two women, three women, I thought it was a good laugh, my friend said knock this off it's too embarrassing, it's dirty. I said no its not it's natural to watch things like that, it's healthy it broadens your mind. We watched lesbians, we watched two men. He said look at that, two men how could they do that sort of thing. I said its part of life M, I said.

P Is this a friend or is that someone you're sharing the house with.

P5 It's the guy I'm sharing the house with.

P Do you ever use pornography, including magazines, as a sexual stimulus, say do you use it to get aroused and then masturbate?

P5 Um, no.

P So you just watch it for something to watch

P5 Just watch it for a laugh, something to watch

P Okay. One of the last things I'd like to ask in this section is what do you think about women with learning disabilities. Do you think they are the same as women without learning disabilities?

P5 Well, yeah, I think all people with learning difficulties, male or female, we are, our genes are the same, we are genetically different to a normal person. A normal person's genes consist of all strands of different things, but a person with a learning disability, a woman, to want a relationship with her is quite hard to understand the way they react to certain aspects.

P Could you give me an example?

P5 Like, um, having a relationship with another disabled person – can they feel the same thing as a normal woman?

P Right. Do you think they can?

P5 I think, I think, deep down they can. In every woman there's that urge to be, you know, to be the top, to be the best woman and I think, um, there is an urge for them to be like a normal woman and they've got this urge for their own gender and the way they look, the way they dress, the way their body language is, um, with E, you know it's all or nothing with her. I like her the way she is and I wouldn't change her for the world

P Ok. Thinking about men and women and relationships, do you think that men are better than women or that they are equal or women are better than men?

P5 That's being sexist that is I can't say nothing about that because we're all equal. You know men, I know men think that they're more intelligently strung and I think men are more, I think women are the same, they think they're a lot better than the male species.

P Fine. Do you think there are some things men can do better than women or women can do better than men?

P5 They can't drive as best as men can! Men concentrate better on the road, I've always thought that.

P Is there anything else you think that men are better at?

P5 Um, () I've always thought personally that I'm better than any man in sex, you know, but its down to how well structured you are and how well you perform.

P In a relationship with a woman, because that's the relationship you are in at the moment, are there some things that you think are your role, or some things you think that's something a woman should do, like who cooks, who cleans?

P5 At the moment I'm living with my friend and we've got a rota there now, 'cause I asked for a rota. In the beginning we were fighting over the cleaning and things like that. If I had a female friend we'd have none of that. It would be down to each other who does what, you know you do the living room one day, I'll do the bathroom the next, I think everyone is up to their own duties, aren't they?

P So you'd split it fairly
P5 We'd share it
P What about things like cooking – are you good at that?
P5 I'm pretty good cook, you know. Give me a wok or give me a kitchen I bring up something. Something into nothing fit for a king, you know. I'm pretty good on the cooker and in the kitchen.
P Good. Okay, the next lot of questions are about relationships. You've already told me that you've got a girlfriend
P5 Yes
P May be you could tell me how you met her and how long you've been going out with her and that sort of thing.
P5 Well I met E. I've known E for a number of years, from school, um, I met in school. She was the sort of person that was getting picked on all the time because of her um, def, deficiency and I always thought she was an odd ball. She would be targeted more than any normal girl would. I used to start hanging round with her, getting to know her, what she liked doing, how many people in the family, um, does she ever go out, you know normal talk and () after school it went a number of years I didn't see E. We kept friends, but you know, it was an element of surprise when we met again. We always kept that close bond between us, if we were close or far away we've always kept each other's instincts at heart and E's a very good friend of mind. Sometimes I don't adjust to her way of thinking and I can adjust myself then, I think I've got to do this right or otherwise she won't like it.
P Does she live locally or ... ?
P5 Yes, she lives only a couple of doors across the road. Where my house is I can see right over the valley and where my house is she only lives across the road a mile across the road.
P So do you see each other often, or ... ?
P5 No, only at work, that's the only time we have contact with each other.
P Why's that?
P5 Because her mother's a very strict on what she does and how she portrays her life at the moment with her illness
P This is the epilepsy ...
P5 Yes
P has her mother always been like that or ...
P5 Yes, 'cause she's a girl her mother, all mothers think of girls / with a boy they think let him get on with it. With a girl they feel more in a protective way for her.
P You said you were at school with her so is she the same age as you or ...
P5 Yes E is forty three and I'm forty two she's a year older than me.
P Ok. Has she always lived at home?
P5 Yes
P So you only see each other at work. Is that every day or ...
P5 Every day. Our relationship is very automical, we kiss and cuddle and have took a chance on life once or twice, you know in work and the results have been dirasterous.
P In what sort of way?
P5 Staff catching us.
P And what have they said or done?
P5 They just said that it shouldn't be, that sort of thing shouldn't be performed in a closed environment like this. Both of us had a row for it and we've learned from that now.
P Is there nowhere you can go together to be private?
P5 No, well I'd like to have her to come over to my house, but it's having someone to bring her over there.
P Right. Do you think her mum would bring her over or ... ?
P5 No, her brother doesn't like me
P Her brother doesn't like you
P5 No
P What about her mum
P5 Her mum do like me, and I respect her family but it's like how E feels about it at the end of the day. If E feels she's invaded then I've got to take that.
P So you've known each other since school. How long have you considered yourself as boyfriend, girlfriend?
P5 Well we're on and off me and E. We're either on / we're like the weather, we're either on one day or we're not.
P Ok. So all you do at the moment is see each other at work?
P5 Yeah
P You said you kiss and you cuddle. Do you ever go out together to the club, pictures or anything?
P5 No she's not allowed out after dark.
P She's not allowed out after dark?
P5 No
P Right, what about in the day time, do you ever go out together or ... ?

P5 No, I meet her in town with her mum, you know. E is very shy, she's a very shy person and she can get really intimidated. She likes to know where she is going and who she is going with and things like that

P Ok. So () do you think you love her?

P5 Yes.

P Okay.

P5 I wouldn't want nothing to happen to her anyway. I think if anything happened to her I would, no I don't know how I would (interruption – door opens and closes)

P You say you love her, what does love mean to you?

P5 Um, affection for another person, and, um, I'll do more, mostly anything for her

P Ok.

P5 I'll be her, like I told her, I'll be like her knight in shining armour no matter how we stand.

P Right. When you think about your girlfriend and you think about your other friends, what is it that makes her special? What do you think is different about her to the other friends you've got?

P5 Her personality

P Right.

P5 Her, ole boost for life and to continue that life you know, um I wouldn't change her, you know if I could find / if I could change her perhaps it would be something that would be loosed. If she changed in any way I think it would widen us more apart.

P So you like her personality?

P5 She's got an awful bubbly, friendly warmth personality and I can relate to E for anything. If I've got a problem I can always relate to her.

P Good. So is there anything else, is it being with her makes you feel wonderful or touching her makes you feel wonderful?

P5 Oh, it's the being with them, being around them. E's not a very touchy person, but once you get her trust and assurance she will let you, you know and now and again I like to have a cuddle with her and I have felt her once or twice. She was alarmed at first, asking what are you doing, you know, and I said I thought you wanted me to do that, you know and now she's more for it. She's not so scared.

P So have you ever had full sex with her?

P5 Yeah

P And did you both enjoy it?

P5 Oh yes. Well without getting caught that was. If we could find some where else like my bedroom that'd be more appropriate. I've slept with loads of girls and had full contact sex and really enjoyed it, and the other person has really enjoyed it as well.

P Good.

P5 They call me the stallion, all the girls do

P Do they?

P5 Yes.

P You've said you don't get time to be on your own together, so sexual acts don't happen very often?

P5 No, we just see each other and enjoy each other's company. 'Cause when there's other people about you can't do much can you?

P No. So what do other people think about you having a girlfriend?

P5 My family thinks it's a good thing. You know, perhaps one day I may feel that I want to go the whole way, you know, I don't know what's going to happen, how I feel at the moment.

P Ok. Your carers, you've said are ok about it?

P5 Yeah

P But her family

P5 No, no

P Have they said why they don't think it's a good thing, or...

P5 Well, they saw, they know she has epilepsy and if anything happened to her over my house, perhaps I wouldn't forgive myself, or perhaps I wouldn't know what to do, 'cause she gets violent fits and she can either hit out like that (makes gesture) and not know what she is doing and things like that ().

P () Hopes for the future are what I would like to ask you about now. You've got a girlfriend, what sort of things, if you could, would you like to do together?

P5 Get married

P What about children?

P5 There's no go on that. There's no way we'll ever have children because it's a full time responsibility and we don't know if both of us, E wouldn't be able to cope with it because of her illness, we couldn't cope with having children. She told me it would destroy our life. It would either kill her or you know, she would never cope.

P Do you think that if she was, if you were given support that you would cope then?

P5 If we had support then, there is nothing stopping us getting married or getting engaged. We've talked this over a million times. E wants to keep it at a minimum pace at the moment.

P At the moment?

P5 Yes.

P What about you, would you like to get married?

P5 Oh, yeah
P And...
P5 Throw anybody at me, Beau Derek or (laughs)
P If you had enough support would you like children?
P5 Yeah, but there's no / I've talked about it a million times with people and they've said there's no way you could have children
P Right
P5 I'd like to have somebody left in my, um, you know, I'd like to have a child that could live after me I could remember him, you know, but it's no way I'd be able to have a child.
P Why do they say that?
P5 Because of the way I am and ()
P Because of your learning difficulty/
P5 Because of my learning difficulties and how the child would respond to the learning difficulties
P Right
P5 I've heard of, you know, blind people having children and the child then looking after the blind person, but with my circumstances of being a slow learner, though my IQ is marvellous, I could never learn to live like a normal person, like anybody else.
P Some people think that it is wrong for people with learning disabilities to have relationships and to have children, what do you think about that?
P5 I think, I think they are talking through their, you know!
P What they are sitting on?
P5 Yes, everybody has a right to form a relationship and have the same feelings and emotions like any normal person.
P Ok. If I was doing a training package for carers about supporting people with learning difficulties in relationships, what sort of thing do you think I should put in it?
P5 Phew, you've got me by there
P What sort of things do you think are the most important things to tell carers if you want to have a relationship?
P5 Tell them to be aware of the fact that we should have the right and respons / the right and responsibility to have a relationship and not to be downgraded and led to believe that we can't have any sort of relationship. You know every body walks through life, you know, there's all walks of life and we're no different to anybody else, we feel that anybody who has a learning disability should have the right and responsibility to live their life the way they want to and to, um, have their say in which way they want to live their life.
P Well that's all the questions I have. Is there anything else you want to tell me about relationships that you felt was important or...
P5 The main thing in a relationship is trust.
P Ok
P5 If you've got trust you know where you stand with people. That's it. I've always thought that, being, uh, to have someone's trust is the main thing to have in life is trust. I feel it's wrong that people get abused sexually and you know, like children, I think that's wrong an all.
P Thank you very much
P5 My pleasure
P That's been really helpful and I appreciate that
P5 I like talking to people, learning about their lives and their / I'll talk to anyone.
End of recording.

5.2.3. Transcript of interview with participant eight

P Just say your name, how old you are and a bit about yourself to make sure that's working properly
P8 Right
P Go on then
P8 My name is CT. I'm 21 yrs old and I'm a big follower... football supporter.
P Right, so what football team do you support then?
P8 L
P Right
P8 I'm going to see them tomorrow in C hopefully
P Are you?
P8 Against MU. We've got tickets and all that.
P I bet they were hard to get
P8 Yeah, you've got to send away for 'em, but we got 'em in the end.
P So who are you going with?

P8 My Dad
P He likes football as well then?
P8 Yeah
P Right, Ok, So do you live with your mum and dad?
P8 Yeah
P Right, ok. And what do you do during the day? Do you work or go to a day centre or do you go to college?
P8 I go to B College every week, every week, every Wednesday to do my course, a computer course
P Right
P8 It's for a year and I'm enjoying it
P So you're learning how to use computers?
P8 Yeah
P What about the other days of the week, do you do anything there?
P8 Sometimes I go ... Sometimes I ask M does he need any help with certain things up the office. Other than that I just relax at home
P That's all right. Ok – one of the first things I want to ask you about is what sort of chances you get to meet people and make friends, so ... because if you don't meet people you can't have a relationship can you?
P8 No
P So what sort of places do you go where you can meet people?
P8 Up here, and we go on trips, weekends away, an er asking people to come up here and meet all of us
P Right, so what sort of places do you go weekends away wise?
P8 I come up here now every Saturday but we're going to O. We got new young ones and we've introduced them to what we do when they first come.
P Right so do you go any other places?
P8 I go O, and I'm hoping to go to E now with Mike an' all that for a weekend away.
P So E would be with (organisation)
P8 Yeah
P So when you go to O who do you go with? What do you do in O?
P8 Um, we talk about this sort of, urm, relationships thing, we talk about it when we go away for a weekend. Its one of the major things that we talked about last year and we said before we went home last year, we said we should come back here and we all agreed that we should go back there next year and talk about it again.
P Right. Because you think it is important?
P8 Yes because it's important
P Right, Ok, that's good. Do you go to, um, places like pubs to meet people or ...
P8 Yeah, sometimes with my, with H and M and all that and when M's around
P Right
P8 Cause M got to come with us to explain what our organisation is about
P So you'll go there and tell people about (organisation)
P8 Just a little bit, but M tells the bulk of it.
P Right, Ok. Do you go to many places, um, where you don't know people or where you might meet new people?
P8 Um, phew, going away, away on trips 'cause that's really nerve racking, cos when we go away now to O like, there's the younger ones and they won't know what were um talking about, but we'll explain to them what we're doing and we'll help 'em
P Right, that's great. If you, um, go somewhere and you like someone and you want to see them again, and they are a new person what would you do? Would you arrange to meet them again? Would you give them your phone number? What sort of things would you do?
P8 Give them my phone number, just give it to them.
P Right, Is that, have you got a mobile phone or is it your mum and Dad's phone number or ...
P8 It's our house phone number, our house phone
P Ok, and do you have many friends phone you at home, or ...
P8 I have H, M and J
P Right. So you get quite a lot of phone calls?
P8 Yeah, if something's coming up and all that.
P Right, Ok, and do you make lots of phone calls as well?
P8 Yeah, I, um, phone J to tell him all these things we're having, all these meetings.
P So you can use the phone alright – you don't have any problems with that?
P8 (unclear)
P Ok. If you're going out somewhere not here or, you said you go out with your Dad to football and things like that, do you ever go out places on your own, say do you go into B on your own or ...
P8 Yeah, 'cause I don't live very far from it, I only live in, um, not far from the sports centre, so I can walk into it and walk back home then.

P That's good, so you do that on your own?

P8 Yeah, I'll do it today now after I've been down the sport centre with Mike now

P Right, ok. What about in the evenings. Do you go out on your own in the evenings?

P8 I never go out to B in the evenings on a Saturday because, mmm... I don't like going down there cause it's um quite late when you're down there and all that and there's people you may meet and they are, they might be offering drugs to you and all that

P right

P8 but I don't take any chances on a Saturday night.

P So do you go into B on other nights/

P8 On other nights with my parents going out for a meal and all that

P So you wouldn't go out on your own

P8 Nah

P Ok. Is that because you feel worried or because your parents feel worried about things...

P8 Both me and my parents feel worried about it because, um, cause, when we um, when we go away I never go down there because I think there is a chance I could have my drink spiked and I never take the opportunity, you know, if they all go down to B I always stay back an all that

P Um, Is there anything else that worries you about going out or is it just sort of drugs?

P8 Its drugs, the most common thing is drugs cause there's a lot of it going around in B at the moment. It's quite worrying

P Right, ok. So you're not scared of getting beaten up or something like that?

P8 I'm quite scared of that but I'm also worried about drugs and all that 'cause that's the most worrying thing at the moment.

P That's fine. Umm, so you go out sometimes with friends...

P8 Yeah

P Sometimes with your Mum and Dad. You say your going to college so do you ... One of the things about going out and meeting people is that it costs money doesn't it?

P8 Yeah

P So, do you think you have enough money to go out and do the things you want to do?

P8 No, it's only on a Saturday when I'm with my, mmm, only on weekends away that I can actually say what I want to say to my friends an' all that.

P Right

P8 Because when I'm up here then I can umm, tell them what's happened in college and all that about my week that's gone by.

P So how much money, you don't have to answer this if you don't want to, but how much money do you have a week to spend on stuff? Do you have much or...

P8 No I only have a certain amount on a Saturday, three or four pound on a Saturday. But it's good I can come up here 'cause I can talk to my friends then

P That's good, but it means you can't go out the rest of the week?

P8 No.

P So how are you going to manage when you go to O, do you get extra money or...

P8 Yeah, but other than on certain weeks on a weekday I don't get the money I need until Saturday.

P Right, so who gives you your money?

P8 My Mam

P Right, ok. Does she save money for you as well?

P8 Yes she saves money

P Ok, you said you wouldn't want to go out late at night because you'd be worried but if you went out you'd go out with your mom or dad or with...

P8 My friends an all that

P Mike an all those, Ok. If you want to take friends home is that ok?

P8 Yeah. I could take M home 'cause M doesn't live far from me

P Right. If you have friends go home are your mum and dad alright about that

P8 Yeah, they're alright with M and H cause my mum knows M and H very well

P Ok, Right, what about if you met someone you found really attractive and you went home with them and you thought you wanted a relationship with them – would that be ok, I mean would it be ok to take someone like that back

P8 No, 'cause you'd have to ask them for their consent first

P Ok...

P8 'cause its one of the most important things that I've learnt when I was in school.

P Ok, well. I'm going to ask you some questions about that in a minute, so we can talk about that if you want. The, um, one of the things is about bodies. A lot of people would like to change their bodies, some women like to loose weight, some men like to loose weight...

P8 yeah

P ... some people don't like wearing glasses, um, some people would like to have more muscles. Is there anything you'd like to change about your body?

P8 No

P So are you happy with your body

P8 Yeah

P Ok, right. That's good. When you think about yourself do you think you're the same as other men or do you think you're different to other men or?

P8 I'm different.

P Ok, so what is it that you think is different.

P8 My um disability and all that, the things I can't do – I've got to have people with me to support me

P Right, and do you think that's ok or does it upset you or...

P8 Its ok but when I'm away an all that, if I see my friends an all that I just say to 'em that, um, there like um my friends an all that you know my friends an all that from my um youth club an all that. I just say they're my friends from my youth club

P Right do you think some people treat you differently because of your disability?

P8 I had it when I was in school when I first started there. When I first arrived there it weren't so bad but and then when my first week started then the following week I just got, I just got heckled, you know I got name calling, I got certain names I didn't like. And there were boys in my old school that were taking the Mick out of my disability.

P And how did that make you feel?

P8 Upset

P Ok, and were you able to do anything about it, to stop it?

P8 I told my parents about it and my mum phoned the school and she said, um, its got to stop and it stopped for a few weeks and it, um, just started up again and eventually then my mum said to them 'that's it he's coming out of, um, staying there every week, he's coming out of there. I went to see the head teacher then and she said, she said you're coming out of residence your going to become a day boarder, you know you can go home now every day. Eventually then I, after I went home it was alright but when I went back fort my to say good bye to them when I went up to say good by to them the boys who were up there were having a row after what they had done to me...

P Right

P8 And eventually then one of them got exclu..., expelled from school. He got thrown out for good.

P Right, do you think that's good?

P8 Yes it was good that he was being chucked out because I told the head teacher who, uh, who knew what problems I had 'cause we explained them and um, he just, uh, said he just said 'I've excluded permanently, you know they're not coming back here for good.'

P So the school you went to, what type of school was it?

P8 Special one, but, uh, it wasn't very good to me at all

P Right, was that in B or ...

P8 In B, yeah

P It was a local one

P8 Its, uh, (name of school) where we used to play (name of another special school) in football but we never done it, I never, I used to watch them, but it was really bad there I was glad to get out of there

P So did you live there for a long time or...?

P8 I was in residence until, I started in '92 and I came out of residence in '96 and then I finished in 2001

P Right, so you're glad to have left school?

P8 I'm glad to have left there, yeah, 'cause my mum said to me 'its too long you've been in there, that school for too long, you're coming out of there'

P Right, so you're happier living at home?

P8 I'm happy now I'm living at home, yeah

P That's good, I'm glad about that.

P8 I still go up there now and again, and see how every, all my teachers are but other than that I was happy to leave there.

P Right, so sometimes people have been nasty to you about your learning disability...

P8 Yeah

P You've said that makes you upset...

P8 Yeah

P if there was anything you could do to change it would you?

P8 I would've gone to a different school but they wouldn't have let me

P Right, Ok. You said there is nothing you want to change about your body...

P8 Yeah

P Do you like your body, are you happy with its shape and every thing?

P8 Yeah

P Right, um, some people might say 'that person is really good looking or something' Do you think you are good looking, do you think you are attractive?

P8 ... phh... yes sort of

P What do you mean by sort of?

P8 My hair and all that, my hair gets really bad sometimes and I've got to have it cut an all that. But other than that I look quite reasonable.

P Yes, you are really like tidy today aren't you? But what do you mean your hair gets bad?

R8 Too long

P Right, ok. So do other people tell you you're good looking?

R8 Yeah

P So are those friends or...

R8 My friends an all that

P Right

R8 If they notice that I've had my hair cut they say good things about it

P Right

R8 Saying they've done a good job

P And how does that make you feel?

P8 Happy then

P Right, ok. So you think it feels good when people tell you you're looking good and that sort of thing?

P8 Yeah

P Ok. So what do you think makes someone attractive to somebody else?

P8 Their good looks an all that

P Ok, right. So that's really positive that people think you're good looking and all that? They notice when you've had things done. This next section is about what you know and what you've been told and your attitudes to things like sex and relationships, ok. Now some of the things in this might be, embarrassing so if you don't want to answer, that's up to you.

P8 Right

P So, one of the first things I want to ask you is have you ever, can you remember having any form of sex education? You've already told me you talked about it at E but did you do any sex education at school or college or ...

P8 We talked about it, small bit about it in school just before we, uh, left, we all left, I left.

P Right. Can you remember what it was about?

P8 About preg, about teenagers getting pregnant, teenage girls getting pregnant and then all these pills they were talking about, we were shown and then uh, they were showing us protection an all that, condoms an all that

P Right, ok. Can you remember, there's a couple of things I wonder if they told you about. So if I talk about them you can tell me if they did? So did they talk to you about how the body changes as you get older through you teenage years?

P8 Yeah

P What sort of things did they tell you?

P8 You, uh, have hair growing on your penis and then right you have hairs growing under your arms an all that

P Ok

P8 We done it separately 'cause the boys were first and then the girls were second, an all that.

P So they split you up

P8 Yeah they split us up in groups, the boys were first in one group and then the girls were in another group

P Right. And do you think that was a good idea?

P8 Yeah. It was a good idea

P Did, you said they split you up, did they tell you about how girls' bodies change as well?

P8 No they didn't tell us about how that happened, we weren't told about that. We were just told about our, our bodies changing and that was it

P Ok, ok, right. Did they talk to you about pregnancy and childbirth? You said they talked to you about teenage pregnancy

P8 Yeah, which was on the rise when I was in school 'cause there was a lot of, uh, a lot of talking about a girl that was about thirteen years old and she'd given birth to a baby girl an all that.

P Did they say that was a bad thing? or...

P8 They said it was quite a bad thing 'cause they said that, I asked the teacher 'how old was the, er, girl when she had the baby' an the teacher said she was thirteen years old, and then, um, all us boys was shaking our heads in disbelief an we were saying, and I said, we said, 'thirteen years old, that's quite, that's too young, an the teacher said, was saying, I just said I wouldn't like to do that to a thirteen year old, no thank you, and that was it then, they just explained to us about how it happened.

P Right, ok. Did they, you said consent was important didn't you

P8 Yeah

P So could you explain to me what consent means

P8 It means that it's like permission, like is it alright if we can have sex or not?

P Ok, that's fine. Um, did they talk about the good things about relationships, like long term relationships and...

P8 Yeah, they talked about that for a little bit, but not much about it.
P So most of it was about the bad things about sex.
P8 Yeah
P Ok. Did they talk about, have you heard about sexually transmitted infections?
P8 yeah, AIDS an all that, we talked about AIDS an all that.
P Ok, so what did they tell you about that?
P8 Well one of the teachers that was in my class, that I was in, he went over to Africa, you know he went over to Africa when we were all on half term, and um, he come back, he had it on a video an all that. He took his video camera over to show us, and then, he was, where he was staying he was asking the people, uh, 'How bad is AIDS over in Africa?' and obviously then the guy that was with him, speaking to him, speaking in the camera was saying its very bad, you know, over one million people died here each, uh, every year, you know and the numbers are growing
P That's a lot isn't it
P8 Yeah
P So how do you stop yourself getting AIDS?
P8 Injections an all that. Sometimes if there is AIDS going around we have injections straight away we have a consent form to see if we can have it or not
P Right, so you think you can have a vaccination for that
P8 Yeah
P Ok, right. Did they talk to you about condoms and safe sex?
P8 Yeah they talked about condoms, but they didn't talk about safe sex an all that
P Ok, did they talk to you about law?
P8 Yeah they talked about the law
P So what sort of things did they talk about?
P8 The consent you know, what, what the law can do, what damage it can bring you if you're in trouble with the law an all that, what damage can happen to you
P Right
P8 They just explained what happens, what could happen
P So did they tell you what things were against the law?
P8 Under age sex an all that
P Ok
P8 They said that's one of the main things that was un, un, that is over the law an all that. If you do that you're in big trouble with the law an all that
P Ok, so how old do you have to be to have sex then?
P8 ...phh, sixteen.
P Ok
P8 That's, um, what they told us in school when we were in school
P That's right. So, um, that's the sex education you had at school. Did you have any at college after that or have you only had it in school?
P8 Well I was supposed to have had it in college, but then I had my, um, accident which knocked me back a bit, so by the time I went back, the um, course was finished.
P Ok, do you think that you had enough information about sexuality and relationships or do you think you should have had more, or?
P8 I think I should have had more 'cause when I was in the college I was supposed, before I had my accident, before I was really looking forward to talking about sex education an then the night before it was supposed to have started, my accident happened an, um, unfortunately then I went back and, um, I was too far behind and I had to give it up then in the end
P Um, I'm sorry about that. Um, some people learn stuff about sex and sexuality from other places as well as sex education. So they might learn it off the telly or off friends or something like that. Have you learned any extra from other places, or...?
P8 um... up here when we talk about rules an all that when we're going away, just before we go away we always have rules an all that. When we go to O now, we'll go up there and next weekend, next Friday, and when we arrive we'll get a board out and we'll start writing rules an all that saying what things we can do and what, what we can't do.
P So what sort of things can't you do then?
P8 um, have, um, have sex unless you've got protection, 'cause that's one of the main things what we're going to talk about next week when we go up now. I think some of us will be saying no sex unless you've got protection
P That's good, because it's safer for you
P8 Its safer for all of you, you know I say I'm not going to be doing it, but some of you may think, its good that we're here and we can mess about, but its not, something bad could happen and I always say wear protection with you 'cause that's important.
P It is. Ok. If I ask you what sort of things sex is can you tell me what sort of things count as sex?
P8 Kissing
P Ok, what else?

P8 Feeling
P What sort of places, when you say feeling, what sort of things do you mean, like cuddling somebody?
P8 Yeah, cuddling and all that
P Touching ...
P8 Yeah
P Ok what else?
P8 Um, phh, um...
P What about masturbation?
P8 Yeah, masturbation that's one of the most common things
P what about touching someone else's private parts? Is that part of sex?
P8 Yeah, that's a part of it unless you've got a condom on it
P Ok Do you think sex is ok?
P8 It's ok as long as you've asked for consent, but other than that it's not 'cause it can land you in big trouble with the law
P Right. Some people think that some types of sexual activity are good and others are bad, ok. Are there any sorts of sexual activity that you think are bad?
P8 Uh, when people are not using protection an all that, 'cause it's quite bad and it can lead to, uh, pregnancies an all that.
P Right,
P8 When, 'cause when we're away I always say protection, always bring protection with you.
P Ok. Do you think it's alright for people to masturbate?
P8 ...
P Do you know what I mean by masturbate?
P8 Yeah
P So is it all right for people to masturbate?
P8 It's all right if they are in their house but in private places its not.
P So, it's okay in private?
P8 Yes.
P Right, what about a man having intercourse with a woman, a man putting his penis inside the woman, do you think that's ok?
P8 In their house it's alright, but in a public place its not
P Ok. What about two women having sex is that ok or is that wrong, or...?
P8 It's ok, but it's their decision
P And two men, is that wrong or right or...
P8 It's their decision as well if they want to do it or not
P Ok. So basically what your saying sex is ok as long as...
P8 Protection is there with you, it is important with it
P And people are happy about doing it and it's in private...
P8 Yeah
P They're the things you've said. Is there anything else important or is that it?
P8 Protection, protection is the most important thing
P Okay
P8 'cause that can land you in the law, with big trouble with the law an all that.
P Do you think sometimes sex can be dangerous?
P8 Sometimes it can be dangerous 'cause the person they have sex with may have AIDS an all that
P Right
P8 Which means then that the person they've given it to, that they've had sex with has now got AIDS an' needs an injection, to uh, they'll have to have an injection just in case the person has got AIDS.
P Do you know where you can get condoms from?
P8 Chemists
P Any where else?
P8 Toilets, an all that
P toilets in pubs?
P8 Yeah
P Some supermarkets sell them as well?
P8 Yeah
P Do you know what I mean by pornography?
P8 Yeah, I've seen that recently on the news an' all that with these people who've got pictures of indecent children on their computers which I've heard a lot about.
P Right, that can be called pornography but its called paedophilia, ok. Pornography might not be breaking the law. It can be pictures of naked ladies, or men and women or it might be a film of men and women having sex, um, have you seen any pornography do you know?
P8 When I was in college, when I was supposed to have done some work for the teacher, 'cause just before I had my accident I was in there writing something down for the house parent and I was writing it

down and there were a couple of my friends messing about and one of them went on to this web-site, the next thing I knew he'd done it and it went right through the college, right through the, uh, the principles office, and, uh, luckily the principle wasn't there but when I actually seen it I just walked out of the class, the computer room an I just said to the houseparent they're looking at, you know, they're looking at, um, pornonraphy and I just said I've just come out of there, I've got nothing to do with it, you know, I've done my work, supposed to have done my work but its gone onto my computer. Obviously then I went into my thing then to put my work away an I could hear him, the houseparent opened the door went in and he said, 'All of you get down, up to your rooms now' and obviously then he was shouting then, but I just said, its nothing to do with me I done no wrong...
P That's ok
P8 'cause I knew as soon as I said to him, 'cause it was on our contract, our consent form, if we done anything bad we'd get chucked out.
P Right.
P8 But because it was the first time they just give 'em a warning
P Right, ok. So you think it's wrong?
P8 It's wrong, yeah.
P If you had a choice in a relationship with someone would you prefer to go out with someone who had a learning disability or someone who didn't have a learning disability or doesn't it matter?
P8 It doesn't matter to me whoever they are.
P Ok, right. Do you think that, um, what do you think about men and women, do you think that, um, men are better than women at some things or do you think that women are better than men, or... what do you think?
P8 They're alright, but some of the time, it's up to them, most of the time its up to them what they can and what they can't do
P Right. So do you think men can do some things better than women?
P8 Some of the time, but other than that they can't do things better than women.
P Ok so what sort of things do you think men can do better than women?
P8 Painting,
P right
P8 washing the car an all that. Then, uh, shopping an all that, but that's my mum and dad that do that. They help each other like get everything that we need.
P Ok. So, I can't remember whether you said you have a girlfriend. Do you have a girlfriend or a boyfriend?
P8 No
P Um, the next questions are about your relationships and what sort of things you would like, then we're nearly finished as you can see. So would you like a girlfriend or a boyfriend?
P8 No
P No?
P8 'cause I wouldn't like to get into trouble with the law an' all that it's too risky, I wouldn't risk it. If I had the protection I would do it, but other than that I wouldn't, 'cause it's so dangerous.
P So if you had condoms and the person was consenting ...
P8 Yeah
P Would you like a long term relationship with them or...
P8 Yeah, if there was protection I would but without protection I wouldn't do it.
P Ok. Um, so, if you met someone you liked, do you prefer boys or girls, or
P8 Girls
P Right, ok. That makes life easier because I can just say 'if you had a girlfriend'. If you had a girlfriend what sort of things would you like to do together?
P8 Go out, spend a week, come, go away on the weekends with ELC an all that and, uh, go out with all my other friends
P alright.
P8 But we'd have to take protection with us, just in case we go out an all that.
P What if the girl turned around to you and told you that she loved you. What would that mean?
P8 That would mean, it's a good sign that the relationship is good
P Ok, so what is 'love' then?
P8 Its, uh, something between a man and a woman and you can, its, uh, quite good.
P So, if you had the choice of any girl, what would you want them to be like?
P8 Good looking
P Right... anything else you'd like them to be?
P8 umm, Nice and cheerful.
P Ok, um, what do you think your mum and dad would think about you having a girlfriend?
P8 They wouldn't mind as long as I had the protection with me like condoms an' all that.
P (Interrupted by M about the need to finish soon due to time.)

Well, there you go, um, right.... We were talking about what sort of things you like them to be like and you said you'd like them to be good looking and nice. Is there anything else you'd like them to be or anything special you'd like them to do or ... ?
P8 um, bring protection with them just in case they want sex an all that.
P Whose job do you think it is to make sure you've got protection, do you think it's the man's job or the woman's job?
P8 The woman's job, the both of them have got to take protection with them if they're going away somewhere
P Right, ok. I know what we were talking about. I was asking you what you think your mum and dad would think if you had a girlfriend.
P8 They would think it was alright unless you haven't got protection then it wouldn't be alright. It would be breaking the law
P If you had a girlfriend do you think it would be alright for you to take her home and sleep with her?
P8 Unless you've got protection, I wouldn't do it, you wouldn't be able to do it.
P Do you think your mum and dad would be alright about you sleeping with a girlfriend at home?
P8 Not unless I had protection with me
P Have you ever talked to your mum and dad about relationships?
P8 We talk about it often, when we come home from O an all that
P Right, and what do your mum and dad say? Do they say they would like you to have a girlfriend or ... ?
P8 No, they just talk about certain things about our weekends away and our relationships and all that
P Okay. Nearly finished. Thinking about the future ...
P8 Yea
P You said you would like a girlfriend
P8 Yea
P What would you like to do together? Would you like to live together, get married, would you like to have children?
P8 We just, uh, would like to go out and see how things run with it. I wouldn't like to do any of the other things unless I had consent an all that, you know, from their parents, the girl's parents an all that
P Right, so it's important that the girl's parents are happy about it as well is it?
P8 Yea
P If the girl's parents are happy about it would you like to live with a girl if you really loved her, or would you like to get married, would you like children ... ?
P8 I'd like to get married but we'd have to wait and, wait till the girl was older for it to happen
P Right, ok. What about children, would you like children sometime?
P8 Yea, but when we are married, I'd have to wait for the girl to be much older then
P Ok. What do you mean by much older?
P8 Because, uh, there was a young girl that went over to Turkey and she tried to marry that Turkish man an all that an I thought I wouldn't like to do that when I'm, uh, to a young girl an all that, I'd wait until they were older.
P So how old would you want a girl to be?
P8 Uh ...25, around that age I would say
P That's alright. Say you meet this girl whose 25 ...
P8 Yeah
P Her parents are happy about it, your parents are happy about it ...
P8 Yeah
P You want to live together. What sort of support do you think you would need, or do you think you'd be able to manage without any support?
P8 We'd be able to manage without any support at all.
P Ok. What about if you had children, do you think you'd need any support?
P8 Yeah
P What sort of things would you need?
P8 Parent's support in case we go out for a meal an all that
P Right, so you'd need somebody to look after the ...
P8 Kids when we go out an all that
P Right, who do you think would be the best person to give you the support?
P8 Parents
P Your parents?
P8 My parents, yeah
P Right, what about people like social services or ...
P8 They would be alright, social services
P Anyone else?
P8 umm ... grandparents
P Right, so you'd make good use of your family?
P8 Yeah

P	Ok. Last question, no sorry, I lied, it's the one before the last one
P8	Yeah
P	You've said you would like a girlfriend and it would be nice if you could get married and have children. Do you think that's going to happen?
P8	One day it'll happen, but not just yet
P	Ok. Right. Now this is the last question. If I was doing a course training some social workers or nurses or people like that about helping support people with learning disabilities in relationships. Sometimes they might say that they don't think people with learning disabilities should have relationships or they sometimes say that they don't think people with learning disabilities should be parents. What do you think is the most important thing that we should tell, um, people who are supporting you? What is the most important thing you would want to tell them?
P8	They are the most important things in our lives an all that
P	Right
P8	You're the most important thing in my life an all that
P	So a relationship is?
P8	Yeah
P	Can you tell me why that is, why is it the most important thing?
P8	Because you can meet a girl, get married and then set up your own family when the, um, girl is older then. But other than that you can't do it unless they're old enough
P	Some people, as I said, might think its wrong for you to have a relationship. What would you say to them?
P8	I'd just say you're breaking the law, you're breaking the law doing that, an that you should always use protection if you're going to have sex with an under age person to stop them getting pregnant
P	Right. Is there anything else you want to ask me or tell me about relationships that you think I've forgotten, or...
P8	No it's alright
P	Alright, Ok, thank you very much. I'll just stop this

End of recording. (43min, 46s)

5.2.4. Transcript of interview with participant ten

Consent for this individual is on tape (omitted from the transcript) as he is unable to sign.

P	Right, yes, I'll just check that's working ok. Could you say a bit about yourself for me?
P10	Yes, my name is A. I come from D near B, I'm 25 years old. I'm also a member of E
P	You're happy about taking part
P10	yes sure
P	everything you say, although I'm taping it, no-one else will get to hear it.
P10	Ok, fine
P	Ok. If there is a question you don't want to answer, just say you don't want to answer and that's ok.
P	The first thing I'd like to ask is what sort of places do you go to meet people, to meet new people. So what sort of places do you go to?
P10	At the moment I go to the local day centre which give mum a break and it's like doing, I can't say small work, but it's like doing therapeutic work, and, um, I don't get paid for it.
P	That was something I was going to ask. If you go to places do you go out to pubs and pictures?
P10	Yes, and to Butlins and E, cause E is part of a group
P	So the times you get to meet people...
P10	E has brought a big change in my life
P	Right. In what way, can you tell me how?
P10	I know I shouldn't say this cause it's rude, I owe a lot of it to M, cause he has a part in everyone's life but especially mine
P	So coming here has helped you a lot?
P10	Yes, cause, I sometimes have mood swings. I take things out on my mother and I know sometimes, I know sometimes I shouldn't but I do. I'm not proud of it but as far as a girlfriend, I'm basically I can see (refers to himself) settling down in a few years time, every time I meet a girl I always want to hurry things along. Like I a met a girl called K. It's a similar pattern, it's great at first, but why I think we split up because I wanted more and she didn't which is understandable
P	Why is it understandable?
P10	Because from a sexual way, I mean I'm not feeling sorry for myself now, but I can't give girls what girls want out of that way and, um, it / I've had small girlfriends but it hasn't lasted because of my attitude basically

PO Because of your attitude
P10 Yes, I know I've got to pick up on it and turn my life around.
P So other than coming to E you don't get much opportunity to meet other people.
P10 Yes, I go out in the village, but sometimes that isn't enough.
P Do you go to places like clubs and nightclubs?
P10 Yes I go to the pub, but as for going to a nightclub Paul, it's very rare cause I've got to rely on transport and pay and all my friends don't live in the same area
P Right
P10 So, by the time you've phoned around on a mobile phone you're out of credit aren't you.
P It is expensive isn't it?
P10 Why I'm not good at friendships is cause of what happened with my parents splitting up
P Right
P10 Cause, I'm, am I allowed to say this?
P Say whatever you want
P10 My mother found out that my father was having an affair and I can't trust a girl. They can trust me, but I know in myself that I want further. It's a bit stupid sometimes. Like if a girl comes up to me and says, I don't know. I can be the girl's friend, Oh God. I can be the girl's company and she's with someone else and I've got a habit of taking them off, off, not taking them off, off, but taking them off someone else
P So pinching someone else's girlfriend?
P10 Which is not fair, cause it's, one boy I done it to is J, and only last week we talked again.
P So it upsets your friendships as well?
P10 Yes
P If you meet someone that you like and you'd like to get in touch with them again, what do you do? Do you give them your phone number, or your address?
P10 well that's hard for me because my mother's always in the house. I'm not having a go at mam but it's not private in the house and to go out everyone stares and says who's that, who's this, A's got a new girlfriend, it's a bit awkward
P So there's nowhere for you to go to be alone?
P10 No, except my bedroom, but if I shut the door my mother would think I was doing something else ()
P She wouldn't be happy about that?
P10 No, I don't think she would, cause, cause me and mam had a tiff this morning and we have them pretty regular. What mam can't get used to and I'm not criticising her is mam can't get used to me growing up to fast.
P How old did you say you are?
P10 25
P So you're an adult aren't you, but your mum still sees you as ...
P10 Yes I'm an adult, but I can't up and go
P Right. Would you like to live on your own somewhere or in a group home?
P10 Well, I, funny how you should ask me that Paul, I like the idea of coming to E cause M and the staff train us up for that. I've got to be honest, though, and I'm not feeling sorry for myself, I've ruined every friendship through my attitude
P What do you mean by your attitude?
P10 Being nasty to people
P Right
P10 I'm not proud of it and I'm not just saying it to have a laugh, ha, ha, ha
P So why do you think, why do you think you are nasty to people?
P10 uh, cause I'm selfish and like everything my way, and, um, ()
P Who has told you that you're selfish or is that something you think you are
P10 me, no mam has told me and she says I need to grow up and, well, huh, my temper is not good, and Paul, it is not as if I'm boasting about it cause I'm ashamed.
P Right
P10 I say the wrong things to people then I get angry quick, but that's A.
P So
P10 it's no-one else's fault, it's just mine. I want to change, but it's like this cloud comes over me. I can be alright one minute and then
P So, you don't get any money for going to the day centre, so if you wanted to go to a pub or something do you have enough money or do you think you don't have enough money?
P10 I think the system is unfair, I think social services is unfair cause, um, we have the system in South Wales which, and that's another thing, I was in college for four years and I wasted my time through larking around using my mouth and not listening to the tutor. But if I knew now what I knew then, I would have tried to turn myself around and work harder
P But then we all have things we would like to change (). So you don't have enough money to go out and do things. You said you have a problem with transport getting out
P10 yes

P If you did go out do you have to be back at a certain time?

P10 Yes, homecare, that's someone who gets me up and puts me to bed. That can be a bit of a drag

P So what time do you have to be home then?

P10 Before ten, yeah

P that's quite early isn't it

P10 Yeah. I've got to say now, talking to you is helping by here realising the, um, mistakes I'm doing.

P Well we all do things sometimes we wish we hadn't.

P10 Yes.

P So say you did meet a girl you liked and you said its hard for you to walk around because people would be saying, oh look he's got another girlfriend and things like that, if you took her home and did take her in the bedroom what do you think your mum would say about that?

P10 She wouldn't be happy, cause, let's start again. Her ways about the birds and the bees are quite different to mine.

P So are you saying that she doesn't think you should have girlfriends?

P10 Yes, she's quite happy for me, it's just me. Like this morning I said a terrible thing to her, cause, I said I won't be back tonight if you're going to be like that, hopefully I'll have a car crash, before I knew what I had said it had come out

P And did that upset her?

P10 () It upset both of us, I don't know if she is speaking to me now. I think it's appalling what I said, you know Paul, Paul, it could land me up in trouble couldn't it?

P Well, if you say things like that it may affect friendships, like you were saying about J and his girlfriend.

P10 I want to change

P At the end of the day that's down to you, may be people can help you think about think about things before you say things. () Going back to relationships and stuff, one of the things I've been asking people is about their bodies and how they feel about them

P10 I know personally I can't have children, because I had a hernia when I was young.

P And how does that make you feel?

P10 I had two () and the doctor said from here you can't have / No my mother said to the doctor will he be able to have children and the doctor said I don't know I can't answer that, but I'm saying no because I've got to be grown up about it, I can't look after children

P What about / do you think you could have children if people gave you enough support?

P10 I'd be alright with support, but I don't think they would do it.

P Are there any things / you know you see men going of to the gym to make themselves more attractive, are you happy with your body?

P10 No, I'm not happy with my legs cause I desperately want to get out of this (indicates wheelchair) and walk

P Right. Have you always used a wheelchair?

P10 Yes, but in school they used to put me on a walking frame.

P And did you manage with that?

P10 Yes, but that was years ago

P But you don't use a walking frame now?

P10 No

P So, if you could you would change your legs.

P10 Yes

P Is there anything you like about your body, is there anything you think that's a really nice part of me?

P10 Well ()

P For example you might think you've got a really nice smile

P10 The other thing I dislike about my body is that I pick up a cup with my forehands, I have to pick up a cup like that, (demonstrates that he picks up cups with the back of his hands) like my friends are supportive in the village but sometimes they will pick up a cup like me and it gets me down

P So do you think they are taking the Micky, or why do you think they do it?

P10 No, they just do it that way. It's going back to the question that I told you about earlier, about my flying off the handle.

P So you'd like to change your legs and your hands. Is their anything you do like about your body? I don't know do you like your face, is there anything you think, that's nice, I want that to stay like it is?

P10 Um, no.

P Ok. If you are chatting to a girl you might think she's nice, I like her. What is it about someone that makes them attractive, what is it?

P10 I've always said in the past, and I'm not criticising anybody, I wouldn't go with anyone with special needs cause, cause I see myself as normal and it's taking, when () excuse me, when you go with someone with special needs you take on her responsibilities and yourself.

P Yes. So you'd prefer to go out with someone...

P10 Normal

P Someone without a learning disabilities or physical disabilities

P10 I don't mind learning disabilities, I mean someone in a chair

P So you are saying you would like to go out with someone who is mobile, who could walk

P10 Yes.

P But, right. What makes someone attractive to you? What is it that would attract you to someone, is it...

P10 Kindness, helpful and all that

P Ok. What about looks, do you think looks are important or kindness is more important?

P10 I've got to be honest, when I was working in the local boy's club I used to get girls coming up to me and saying A give me a kiss and I'd say no because you are under age.

P Right

P10 They'd have to be in their twenties.

P So that's the age you'd like someone to be?

P10 Yes, not fifteen and that

P So someone who is a similar age to you? Right. Do you think that / You've just said you had girls coming up to you and asking you for a kiss and things like that, do you think that people think that you're attractive?

P10 No

P Why's that?

P10 (laughs) cause, cause, uh, definitely not, because I, I don't go anywhere, I always stick around in the village

P Right. So what do you think other people think about you? Do you think they think you are a really nice guy or do you think they see / what do you think people think about you?

P10 I don't care what people think about me. If they can't take me as AMc then don't bother at all.

P Right

P10 They are either with me or against me.

P Ok. The next thing I'd like to ask you about is what knowledge you have about sexuality issues and whether you have had any sexuality education...

P10 Well, I, as you are doing a survey about sex I do have feelings, I do have, can I say?

P You say what ever you want, however you like

P10 I do get a, a hard on. It's hard for me to pick up with somebody and like they say take home for a coffee because mam is always there.

P Yes. Did you have any sex education at school?

P10 Yes, but, there again, I was too ignorant in school. I take, I takes sex education more serious now than I did when I was in school, cause I used to lark about then.

P Right

P10 Cause words in school, like an erection, I used to burst out in laughter, but now I take it serious.

P Right. Can you remember what they told you in school about sexuality?

P10 They told us about sperm, they told us about where babies are from, and, um, but mainly, but the main thing is that I didn't take it serious enough because / it's like one girl phoned me and me and my mother, my mother said someone's on the phone for you A and she's in love. The last time I finished with K it devastated me, I couldn't do my work and attend, I was taking my moods out on everybody.

P How long had you been going out with K

P10 A long time. The biggest thing is that I asked her to marry me and she said yes then she went behind my back and she went with R and J.

P Right. Thinking about the sex education at school, you said that you didn't take much notice, but did it talk about the difference between men and women...

P10 Yes

P Did it talk about how the body changes as you got older?

P10 That's a different part, that was a different part in school, cause they showed us a woman's down below and a man's down below and I found it quite embarrassing

P Ok. Did they talk about how the body changed as people got older and became teenagers?

P10 Yes, like, I mean () be honest with you Paul I can't remember because I was 15 at the time.

P That's ok. Have you had any sex education since then?

P10 Yes we went on a course last week to O.

P And what sort of things did that talk about?

P10 Having sex, treating a girl right, looking after her, one night stands and all that.

P So it talked about relationships as well as just having sexual relations.

P10 Yes.

P And did it talk about things like consent?

P10 Yes, it talked about consent, saying no and saying yes

P Ok. What about law? Did it say that some things are against the law and somethings are ok?

P10 Yes

P Can you think of any things that are against the law?

P10 Against the law is when you rape somebody, that's against the law forcing them to have sex and giving them drugs and all that

P Ok. Did it talk about sexually transmitted...

P10 Yes, AIDS and all that

P Right. So, you know how not to get infections?

P10 You've got to be, I got to be realistic, it's not as if I could have sex because of my condition

P Ok. How does that make you feel? Does it make you angry, or upset?

P10 No, 'cause I know I couldn't do it

P So.

P10 Sometimes it makes me angry, cause I feel, how can I say, mams always back and forth and says do you want a drink, do you want something to eat, now I'm not criticising mam now cause me and mam are different ages. I mean I'm 25 and mam's a lot older than me, so mam, no, I'm not being rude when I say this, but mam's been through the system and I'm only coming up to that ()

P What do you think you mum would think about you having a sexual relationship with someone, do you think she'd think it was ok

P10 I think, I don't think she'd mind if she was honest, but if the girl's playing about with other boys, carrying on behind my back I think mam would be nasty about it.

P if you had a girlfriend and she came back to your house and you both went into your bedroom do you think you'd be able to sleep together

P10 Mam doesn't carry on at me for shutting the door but when my father was there he didn't like it cause his family are from a different generation. He'd even turn sex documentaries off. Not just turn it off, it'd be 'switch it off now, You're not watching that, I don't care, switch it off now'

P But your mum's alright

P10 Yeah, I can talk to mam about anything () sexually, but the thing that worries me about sex, and I know I shouldn't say it because I feel embarrassed telling you is I have a load of sores down there (points to buttocks) and I couldn't have sex anyway

P Are they being treated, do you have something for them?

P10 They're part of cerebral palsy

P It's not just a sore you can have cream on or something?

P10 If, if I wet myself then I blister straight up which () it doesn't help.

P Is it very sore?

P10 Yes, can't sit down sometimes, I'm in agony

P Do you think this may be why you are sometimes bad tempered, because you're hurting?

P10 No, there's no excuse for it, some people say he's like that because he's special needs, do you mind if I say this,

P No

P10 I go bollocks, its not because I'm special needs, it's because I like to get my own way and I tell people the truth.

P Ok. If somebody said they'd like to have sex with you, what do you think they mean? What does sex mean to you?

P10 Intercourse,

P Intercourse?

P10 the full thing.

P Ok. So are there other things that are part of sex?

P10 I wouldn't mind doing it with a girl if she's honest, but if she plays around with others then I wouldn't want to do it.

P Ok. Do you think sex is ok?

P10 Yeah

P Do you think there are any types of sexual activity that are wrong, some people think...?

P10 That's only the older generation that think that. It's because, only because the older generation say one thing and do the other, like I give you an example now, my grandparents say sex is bad, sex is this, only cause they watch bloody dramas, only because they watch make believe dramas like Eastenders and Coronation Street. We're not dramas we're everyday people.

P So do you think that any types of sexual behaviour are wrong, for example, some people think it's wrong for two women to have sex...

P10 The only expression that my mother hates, and she hates it very strongly, is when she sees two of my friends (unclear) together and she goes really berserk.

P Right. So do you think it's ok for two women to have sex?

P10 No, definitely not

P Ok. What about...

P10 If they love each other yes, but if they don't ()

P So it's about whether they love each other is it?

P10 No, I'm not saying that, if one is straight and the other is bent and the one tries to turn the other one that's wrong.

P Ok. But if they are both, as you put it, bent, that's ok is it?

P10 Yeah.
P You said you think your mum would be alright about you having a sexual relationship...
P10 My mum has seen me snogging a girl and she's taken no notice of it, but my father would question it.
P Ok, what about people down the day centre, what about the staff there? Are they ok about people having relationships?
P10 I don't really talk to them cause E is a different thing to the centre. I keep my E career out of the centre.
P Right
P10 What it is Paul, I see myself as a member of a big squad here
P It is very friendly and positive here isn't it?
P10 Yes.
P You said that you had sex education at school ages ago, that you've done some recently at O.
P10 Yes, I felt embarrassed then
P You felt embarrassed then?
P10 Yes, but not really embarrassed, once I got to grips with it, I like talking to people one to one like I'm talking to you, but in big groups I get embarrassed.
P I can understand that. () So do you think now that you've done some stuff at O that you have enough sex education or do you think you should have more information?
P10 Well, you see, it's like I said to you earlier Paul, the system is wrong as far as social services is concerned. There should be a teacher, not every week but going into the centres and speaking to the people about sex education. But, there again, the staff ages in the centres are wrong, like 60s, 50s
P So they're mainly older people working in the centres?
P10 I work with old married men and women
P This is at the centre?
P10 Yes
P Which centre do you go to?
P10 L
P Right. () Do you think that sometimes sex can be dangerous?
P10 yes, but you've got to take the right precautions haven't you?
P Right. So what sort of precautions would you take?
P10 Condoms
P Ok. Where would you get them from?
P10 The chemist.
P Ok. If I ask you what pornography is can you tell me
P10 I can actually tell you.
P Ok. So what would you say pornography is?
P10 It's people that are interested in children. I can actually tell you a good story, if you want to hear it. I was actually working in the boy's club and this boy got me to perform sexual acts. He said go on, you won't get into trouble. I told my mother and it cost me my work experience, cause I wasn't allowed to work there any more, not by social services, not by the owner, but by my mother.
P What did he get you to do?
P10 Oh, God ()
P That's ok.
P10 (laughs) He got me to / he said show me how you w.
P Um
P10 It was getting () pretty bad
P Right. So did your mum tell anyone about that?
P10 No, cause I told her not to make a fuss, because I was big friends with the owner and I known the owner for years.
P So your mum just stopped you going there?
P10 I stopped myself going there more as my mother cause it was working with younger children, about 15 year olds, sixteens.
P And you didn't want to work with them?
P10 No
P Um, do you ever...
P10 And in the end I was, sorry to interrupt, I was getting called 'gay', 'Where's you boyfriend A' I got really upset, and because I used to wear pads they used to take the piss out of me.
P That's not very nice
P10 No
P () Do you ever look at pictures or films of people having sex, like magazines
P10 you know you asked me about pornography, earlier, I don't really like that, if I didn't leave that boy's club it would have made me in the same league
P Why would it have made you in the same league?
P10 () Cause the boy in question was asking me to do things

P Things with him?
P10 Yes, and a friend of ours
P Ok. () So did you want to do it or was he making you do it and you didn't really want to do it?
R10 () well, I had a few problems at the time in the house and I didn't care what trouble I was getting into, but, but now I do, because I think if I don't stop now I could land up in serious trouble.
P What do you think about / you said if you had a choice you wouldn't want to go out with a woman with multiple needs, but you wouldn't mind going out if the woman just had a learning disability, is that right?
R10 yes
P Do you think that women with learning disabilities are the same as women without learning disabilities, or...
R10 No
P What's different about them?
R10 I've got to be careful how I say this.
P Say it however you want.
P10 At the moment, I just, well a couple of weeks ago I broke up with K and it affected me bad, cause, I was there, but I weren't, I was taking my mood swings out on mam an all that. I would say, like there's no / if you go out with someone without a learning disability then you're normal.
P Ok. Do you think that men are better than women?
P10 No
P Ok. Do you think that women are better than men?
P10 I think we're both the same as far as mood, as far as tempers are concerned.
P Ok. Do you think that women are better at some things than men or men are better than women at some things or do you think they are the same?
P10 (laughs) They're the same.
P Ok. So at the moment you haven't got a girlfriend?
P10 I've just asked somebody out.
P And what did they say?
P10 She said she'd think about it, but I know from personal experience what the answer will be, no.
P So you'd like a girlfriend
P10 Yes, it's not that I can't trust her, I can't trust myself
P What, to find someone else?
P10 No, it's easy to find another person, all you've got to do is go out there and work hard at your friendship, but I've / it's like I've had so many, right, and they dump you.
P that can't be very nice, being dumped?
P10 No
P So, your last girlfriend, can you remember how long you were going out with her, was it a couple of weeks, a couple of months?
P It was back in the summer it was, yes
P10 mam didn't help, she didn't give her a chance
P What do you mean, mam didn't give her a chance?
P10 () mam reckoned she was encouraging me to drink (unclear)
P To drink?
P10 To drink more, you know shorts and all that
P And your mum didn't think that was good for you?
P10 Yeah, and the public didn't give her a chance
P In what way?
P10 How can I put this, I've never been on a bender, because I don't like going on a bender, but people in the village would tell my mam () I think the less people know about you in the city or the town or village the better
P I suppose you can get away with different things if you live in a bigger place can't you
P10 Do you have the same problem?
P I don't live in a village, I live in a town, you may bump into some people you know but most people that are around you don't know, so it's not the same as for you.
P10 No
P You know when you had your girlfriend what sort of things did you do together
P10 Kiss and that, I was more for her, but the first day we wanted to be alone my Mother said do you want to come to a barbeque at a friend's house. Do you think its wrong I feel like this about my mother?
P There's times when we all fell angry with people that are very close to us and if we are with people a long time we can all get angry or frustrated and say things that afterwards we regret and wish we hadn't said. We all have arguments with people don't we it doesn't mean you don't care about them anymore.
P10 Yes.
P So you used to kiss and things. Did you do things like go to the pictures together, what other sort of things did you do?
P10 No, cause of transport issues, and um, money costs an all.

P If somebody said they loved you what would that mean to you?

P10 There again, A would take it in the wrong way

P What do you mean, in the wrong way?

P10 If someone shows friendship I would see it as a different thing

P Right. () What sort of things did you like about your girlfriend, what was special about her

P10 She was special to me

P What made her special?

P10 () um, because she listened to me

P She listened to you. That was important?

P10 Yeah

P What about, her looks?

P10 Yeah,

P So what is it that attracts you to somebody, what is it that makes you think Oh, I'd like to go out with them?

P10 Um, their behaviour

P Their behaviour?

P10 Yeah

P () The rest of the questions I'd like to ask you are about the future really. You said you'd like a girlfriend?

P10 Yeah

P What sort of things would you like to be able to do, I mean would you like to live with them, get married?

P10 I, think () I think, I think to be truthful I think having children is great but you're so tied then aren't you. You got to be home at a certain time and put dinner on the table, I don't think I'd be able to do that.

P Right. Would you like to live with a girlfriend?

P10 I've got to be honest, I don't like children anyway.

P You don't like children?

P10 No.

P If you had a girlfriend would you like to live with her or get married?

P10 live with her

P Ok. Do you think that might happen?

P10 No

P Why don't you think that'll happen?

P10 Because I need a lot of personal care, someone to get me up and put me to bed

P And how do you feel about that?

P10 Fine

P So you don't think you'll ever live with a girlfriend

P10 No, if I'm honest, I can see myself living with mam or in residential care

P Do you think you miss out because of that?

P10 I miss out because mam is so over-protective.

P Is that why you get angry with her sometimes?

P10 Yes, That's the main reason and because she doesn't keep our rows to ourselves she gets my Nan involved and my two uncles and my friends. () She tells me not to get other people involved but she does

P Right. How does that make you feel?

P10 Angry

P Um.

P10 I've been close to going into care because of my attitude, but if mam would change, perhaps I could come on but she's not doing it.

P Um () One of the things I would like to do is a training pack for carers who support people with learning disabilities...

P10 That's what I like about E, cause M and the staff treat us equal

P Ok. If you were training someone to work with you or with someone else what's the most important think you would say that they should do?

P10 Do you know Paul there is a direct payments for our care?

P () And you think that's important so people can choose their own carers?

P10 Yes

P Right. Do you think that carers should support people with learning disabilities in sexual relationships or do you think it's ok if they don't?

P10 Yeah, they should support people

P Is there anything else you would like to say

P10 No

P Thanks for giving up your time

Recording finished 63:45

5.3. Appendix Three: Ethical review checklist

5.3.1. Details of Project Organisers

Name of main organiser:

Paul Wheeler.

Names of those involved and role (and affiliation, where non-Tizard)

Michelle McCarthy, Tizard is Paul Wheeler's supervisor for this work.

5.3.2. Title of project

The expression of sexuality by men with learning disabilities: A study of their attitudes, experiences and aspirations and those of their carers (this is currently the working title of my MPhil/PhD)

5.3.3. Purpose of Project

During the last three decades, there has been considerable interest in the subject of sexuality in relation to men and women with learning disabilities. The focus of this has essentially been on preventing abuse and reducing levels of 'sexually challenging behaviours'.

However, little attention has been given to either supporting people with learning disabilities in the expression of their sexuality or ascertaining their attitudes, experiences and aspirations in relation to this subject. The project will explore the experiences of men with learning disabilities as to whether the expression of their sexuality and development of personal relationships has been discouraged, ignored or facilitated by their carers. It will also explore how they perceive their sexuality; what their aspirations are concerning personal relationships and the expression of their sexuality and what they believe is necessary in order to for them to be able to fulfil these aspirations.

It is generally recognised that carers play a considerable part in the formation of client's self perceptions and in shaping their attitudes. Given this, the project will also explore the attitudes of carer's towards the expression of sexuality and development of personal relationships by the men they care for.

The results of the research will be made available to all participants and will be further disseminated with a view to encouraging best practice.

The longer-term aim of the project organiser is to develop models of good practice and training materials aimed at improving practice in relation to the support of sexual expression and personal relationships by men with learning disabilities.

5.3.4. Conduct of Project

a) Location

A variety of residential and day services in South Wales

b) Brief description of participants (and number); control participants (if any) and number

- Men with learning disabilities using self advocacy groups will be invited to participate in a focus group
- Approximately 20 adult men with learning disabilities will be interviewed.
- Carers from a parent's organisation will be invited to participate in a focus group.
- Carers from a variety of service providers will be invited to take part in a focus group
- A survey (supplemented by some interviews) of carers (formal and informal) will be conducted.

c) Brief account of how requirements of the Data Protection Act will be complied with.

- Confidentiality of participants will be respected. Unless people admit to having committed an act that may be a criminal offence any information provided by the informant will not be divulged to other sources in a manner that enables the informant to be identified.
- Information held on paper and on computer will be anonymised
- Information on participants names and addresses, transcripts and completed survey tools will be stored in a locked cabinet

d) Expected start date and duration

- November 2002 for 6-8 months

e) Frequency and duration of procedures

- The research will be in two main phases. Firstly the research involving men with learning disabilities and secondly that involving carers.
- Focus group sessions will be undertaken at a time convenient to those invited.
- Questionnaires will be distributed to carers via a variety of organisations.
- Interviews will be carried out at times mutually convenient to all parties.

f) Payment of participants (if any)

- Men with learning disabilities taking part in focus groups will be paid for their travelling expenses and light refreshments (e.g. tea/coffee/biscuits) will be made available at the focus group session.
- Carers participating in focus groups will be not be paid for their travelling expenses but light refreshments will be made available at the session.
- It is envisaged that interviews will take approximately one hour. A token payment of £5.00 will be made to compensate men with learning disabilities for their time.
- Carers will not be paid for either completing the questionnaire or for participating in in-depth interviews.

g) Source of funding (if any)

- The funding for the project will be met from the project organiser's personal PhD expenses budget.

h) *Brief account of methodology / techniques (please give summarised account of measures to be used. If using a standardised questionnaire, please include an example of it)*

Stage 1a:

Men with learning disabilities will be contacted through two advocacy organisations in South Wales and asked to participate in focus groups. They will be given the opportunity to discuss their experiences, attitudes and aspirations in relation to the expression of their sexuality and personal relationships. Their views will be used to adapt the topic guide for the in depth interviews that form stage 1b of the research.

Stage 1b:

Semi-structured in-depth interviews will be used with men with learning disabilities willing to participate in the research. A draft topic guide is appended to this document (Appendix 1).

Stage 2a:

Informal carers of men with learning disabilities belonging to a parent support group in South Wales will be invited to participate in a focus group. They will be invited to express their attitudes, concerns, etc towards the sexual expression and personal relationships of the men they care for. Their views will be used to adapt the topic guide for in depth interviews to be carried out in stage 2c.

Formal carers of men with learning disabilities from a variety of service providers will be invited to participate in a focus group. They will be invited to express their attitudes, concerns, etc. towards the sexual expression and personal relationships of the men they care for. Their views will be used to adapt the topic guide for in depth interviews to be carried out in stage 2c.

Stage 2b

A questionnaire will be used with formal and informal carers. An outline of the subjects that will be included in the questionnaire is appended to this document (Appendix 2). Respondents will be asked whether they would be willing to participate in in-depth interviews.

Stage 2c:

A selection of carers who expressed a willingness to participate in in-depth interviews will be invited to do so. The interviews will be loosely structured around the same topic areas as the questionnaire, but offer participants the opportunity to more fully express themselves.

5.3.5. Ethical Considerations:

This section should address at least the following:

1. *The rationale for the decision to pay, or not pay, participants and the likely impact on participation.*

Men with learning disabilities who participate in focus groups will be paid their travelling expenses and will be provided with light refreshments. The refreshments are a token of gratitude for their participation but would not be seen as being sufficient incentive to cause people to take part if they do not really want to.

A token payment will be made to men with learning disabilities who participate in in-depth interviews. This is to demonstrate that their time is valued. However, they will not be advised of such payment prior to agreeing to be interviewed in order that payment is not regarded as an incentive for participation.

The researcher does not have sufficient funds in order to make payment to carers. However, even if such funds were available no payment would be offered for the reasons detailed below:

Carers who participate in focus groups are not being offered travelling expenses as it is felt that this will mean that only those interested in participating will do so. They will, however, be offered light refreshments at the focus group session as a token of appreciation for giving up their time.

Informal carers who participate in in-depth interviews will not be offered payment as this should ensure that only those who are interested in the research will participate. Formal carers will not be offered payment, as they will be involved during their normal hours of employment.

2. *Any risks to participants from potentially intrusive procedures. Please consider physical risks (e.g. injury), psychological risks (e.g. people becoming upset), social risks (e.g. embarrassment or rejection).*

Men with learning Disabilities Focus Group:
There is no risk of physical injury to participants arising from the research.

There is a risk that the men may become embarrassed about speaking about personal relationships. However, men invited to participate will be members of a self-advocacy group and should thus be used to speaking about sensitive issues. Additionally, the researcher will emphasise the fact that participants can withdraw from the focus group at any time. If participants become embarrassed or upset, the researcher, who is experienced in working with people with learning disabilities will offer support. He will also offer to obtain support from their carers for them, or where appropriate and with their permission will refer them to appropriate agencies. If this is the case, the researcher will contact the individual at a later date to ascertain that they have received appropriate support.

Although the research is not concerned with abuse, it is possible that participants may make disclosures of ongoing abusive relationships. Participants will be advised at the beginning of the session that if they make such disclosures such information may need to be shared with appropriate professionals and that adult protection measures may have to be followed. If participants disclose such abuse, this will be discussed with them at the end of the group and relevant actions will be explained to them. Other than such disclosures, participants will be advised that the discussion is confidential and that their identities will remain confidential.

Men with learning disabilities: In-depth Interviews.
There is no physical risk to interviewees as a result of participating in the research.

Men participating in the research may be embarrassed by discussion of personal issues. They will be reminded that they may withdraw from the interview at any time and that they can 'pass' on any question. However, the fact that the interview is to be relatively unstructured, with the interviewee being given the opportunity to talk freely around the issues on the topic guide, should mean that the interviewee does not feel coerced into answering questions they find embarrassing.

Men may also express emotions such as anger or sadness as a result of the discussion. They will be treated sensitively by the researcher who will check frequently as to the participant's willingness to continue. If the participant becomes upset or angry, the researcher will offer to terminate the interview and will also offer to obtain support for the interviewee.

Carers' Focus Group:
There is no risk of physical injury to carers arising from the research.

Carers may well have strong feelings about the issues raised and may express emotions such as anger, sadness, or frustration. The researcher will at all times seek to be sensitive and empathetic towards carers. Carers will be advised at the start of the group that they may withdraw at any time and that they are under no obligation to discuss matters they find upsetting.

Carers will be assured of confidentiality (subject to the exception of disclosure of abuse).

Carers' Interviews
There is no risk of physical danger to the interviewees. However, given that some interviews may take place in the interviewee's home, the researcher may be at some risk. He will carry a mobile telephone with him and where possible will make appointments during daylight hours, as per the Tizard guidelines on personal safety.

As with the focus group, carers' may have strong feelings about the subject matter and may feel a variety of emotions. Again, the interviewer will remind interviewees that they may terminate the interview at any time and that they can 'pass' on any question. As with the interviews with men with learning disabilities, the interviews will only be loosely structured, thus the interviewee will not be posed with questions they find embarrassing.

3. *The intended feedback to participants (and, where relevant, to other service users/carers/advocates/services) and how this should be given.*

At the end of the project the data will be analysed and a brief report of the findings written in simple English. This will be made available to all participants via the self-advocacy organisation / parents' organisation/ day or residential services. At a later stage the researcher hopes to disseminate the research in conference presentations and in an appropriate journal.

4. *Issues relating to confidentiality during the project, and in any subsequent data analysis, conference presentations and publications.*

See above section 4c. Any reports, conference presentations or publications will use only anonymised data thus preventing identification of participants.

5. *Anticipated difficulties, particularly those relating to power imbalances between the researcher and participants, and how these will be dealt with. If you think the service user complaints slip provided by Tizard Centre will not be suitable for your research participants, please amend it and attach a copy with this proposal.*

Men with learning disabilities:

The researcher recognises that there is likely to be a power imbalance between himself and these participants. However, he is experienced in working with people with learning disabilities and will seek to reduce such imbalances, for example by dressing informally, using his first name, and arranging for the focus group / interviews to take place at venues at which the interviewee feels comfortable at a time convenient to the interviewee. The format of the focus group and interview will also enable men to tell their own stories thus giving them considerable control over the interview. This format will also reduce such difficulties as are sometimes encountered in interviews with men and women with learning disabilities such as acquiescence. The researcher will also emphasise the right of participants to withdraw from the research or to decline to answer any question put to them. The complaints form will be discussed with them prior to commencement of the interview/focus group.

Additionally it is anticipated that some interviewees may think that the researcher will be able to change things for them. Whilst this is a long term aim, the researcher will not immediately act as an agent of change and this will have to be made as clear as possible to the participants when obtaining their consent.

Carers:

Again there may be some power imbalance between the carers and the interviewer. The interviewer will seek to address this for example by dressing informally, referring to himself by first name, and arranging for the interview to take place in a venue of the participant's choice. Again, the participants will be reminded of their right to withdraw from the interview/ focus group at any point and the complaints form will be discussed with them prior to them taking part.

6. *Information about any other ethical procedures which need to be, or have been completed (e.g. permission from service providers).*

The main researcher will wait for clearance from Tizard ethics committee prior to contacting service providers / advocacy groups / parent groups. He does not foresee difficulties in relation to research with the carers, but anticipates that he will have to comply with ethical requirements of service providers. These will be determined and addressed once he has made contact with them.

7. *How the research meets the four main ethical principals of research, namely non-maleficence (not causing harm), beneficence (doing good), autonomy (treating people with respect and giving them information so as to make their own choices) and justice (who will be advantaged / disadvantaged by the research)*

Non-maleficence:

The use of procedures relating to consent and complaints and the ensured confidentiality of participants should protect participants from harm. The researcher recognises that the nature of the research is sensitive and may result in participants becoming embarrassed or experiencing a variety of emotions. However, the researcher will at all times treat participants with respect and empathy and will remind them that they may withdraw from the research at any time. He will also offer to contact appropriate support services if participants desire this.

Beneficence:

The research will allow men with learning disabilities and carers of men with learning disabilities to voice their experiences, attitudes, aspirations and concerns in a neutral setting without fear of repercussion. The publication of this work will provide service providers with an insight into the views of participants and may result in positive change for service users and carers. In the long term, the project organiser intends to develop models of good practice and training materials aimed at improving practice in relation to the support of sexual expression and personal relationships by men with learning disabilities.

Autonomy:
All participants will be given a letter detailing the nature of the research (Appendix 3). It will be emphasised that participation is voluntary and that service provision will not be affected adversely as a result of a persons' decision to participate or not.
Consent will be sought from all participants, both at the point of contact and immediately prior to the commencement of the focus group session / interview.

Justice:
Participants will not be disadvantaged by taking part. It is hoped that they will be advantaged in the short term by having the opportunity to have their views heard. In the longer term it is hoped that the research will result in a better understanding of the experiences, attitudes and aspirations of men with learning disabilities in relation to the expression of their sexuality and will result in their receiving improved support in this area.

In relation to carers, again they will have the opportunity to express their attitudes, concerns, etc. It is hoped that the publication of the expression of such concerns may also result in their needs around this subject being better met by services.

8. *How the research will pay attention to cultural issues: e.g. include the experiences of people from Black and ethnic minority communities; be respectful of cultural differences; provide appropriate interpreters, where necessary (NB. Researchers should note that this often involves more than simply finding someone who speaks the same language).*

Although there are Welsh speakers in South East Wales, their numbers are limited and most, if not all, speak English. It is also likely that there will be participants from Black and other ethnic minority groups whose first language may not be English. As there is no budget for paying for interpretation services, only people speaking English will be invited to participate.

However, the researcher will seek to invite participants from a variety of ethnic groups, religious denominations, etc., and will be sensitive to their cultural / religious identity, for example by obtaining advice prior to interview as to any matters that it would be inappropriate to discuss, etc.

9. *The level of user participation / involvement in the research design, data collection and analysis, and any implications for the research.*

Service user participation in the research design will be limited to the fact that the views they air in the focus group will be used to shape the topic guide for the in-depth interviews.

The only person undertaking the data collection and analysis will be the main organiser as the research is to be used for an MPhil/PhD and he does not have funds to employ research assistants.

5.3.6. Consent:

This should address at least

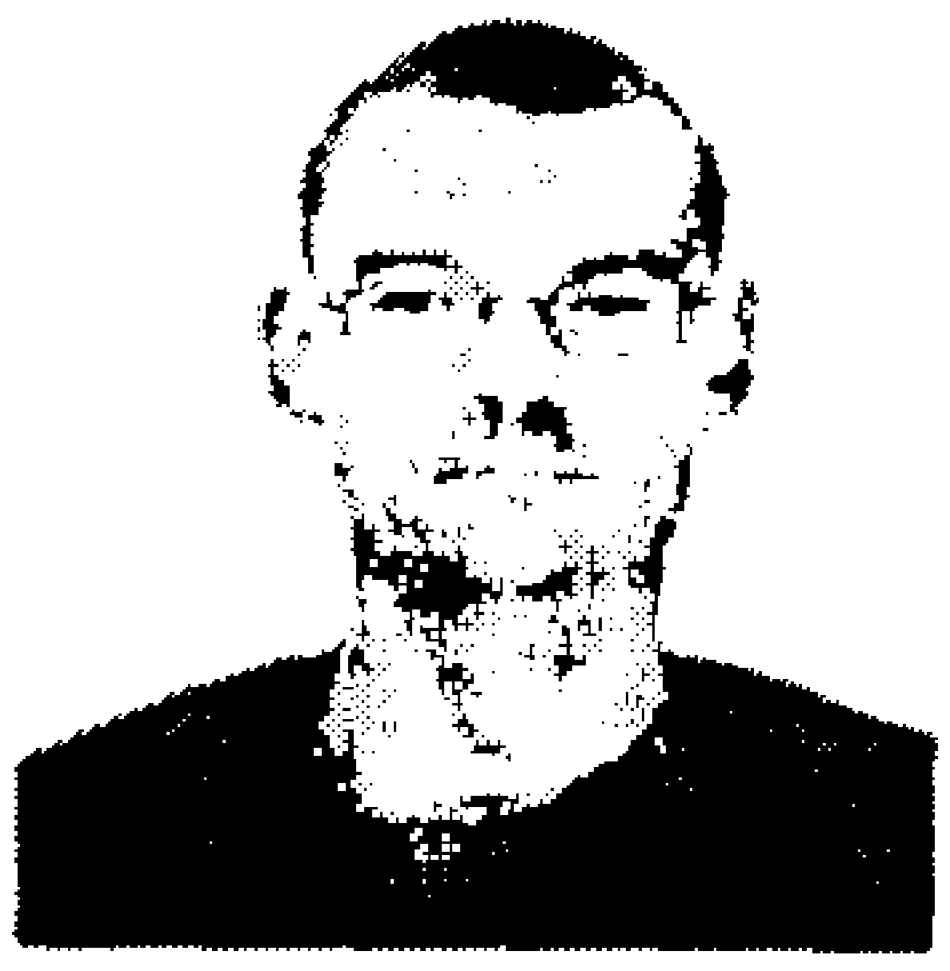
1. *How it is intended that informed consent will be obtained from participants (materials relating to consent, e.g. consent letters should be attached).*

As I am primarily using focus groups and interviews in this research it is anticipated that most of the participants will be able to provide informed consent. The nature of the research will be explained to them verbally by the researcher at an initial meeting. At this time, those showing an interest in participating will be given a letter explaining the nature of the research (appendix 4) which they may take away with them. They will then be contacted again to check they are willing to take part and arrangements will be made for a meeting. The consent form (appendix 5) will be gone through with them at this stage and they will be asked to sign the form. If they are unable to sign the form, but are willing to participate, they will be asked to signify this on a tape solely for this purpose. The issue of consent will be checked at any subsequent meeting.

2. *Procedures for gaining permission from participants who are unable to give informed consent (materials should be described, and where possible, attached).*

I will not be interviewing severely or profoundly disabled individuals. Whilst it is possible that carers may discuss their attitudes, fears, etc in relation to the sexuality of such individuals, this would be in an generalised anonymised form. No observations or intrusive measures will be undertaken in relation to individuals unable provide consent.

5.4. Appendix Four: Information sheet for, would be, participants



My name is Paul Wheeler. I am a research student at the Tizard Centre at the University of Kent. I am doing research with men with learning disabilities. This is to get to know about things that are important in their lives.

I am trying to find out about men with learning disabilities' personal relationships. I might ask questions like:

- Do you have many friends?
- Do you have any special friends (girlfriends / boyfriends)?
- How did you meet your friends?
- What hopes do you have for your relationship, e.g. would you like to get married?
- What do other people feel about you having a special friend?

Some of the things you might want to talk about may be embarrassing, so I would talk to you in private. This could be at your home, at your day service or anywhere you would like to choose. I will keep your name and address private and no-one will know what you talked about. Talking to me will not affect the services you receive in a bad way.

Would you like to help me with my research? You won't have to answer questions you don't want to. If you say you will help me and then change your mind that is OK. You can change your mind at any time.

You can take this letter home and show it to someone like your carer or advocate. If you or they want any more information about the research, phone me on (07977 134998) or e-mail me at pnw2@ukc.ac.uk .

✂---

Personal relationships research (Service Users/Interview)

If you would like to help me with my research please tick (√) here______
If you don't want to help me with my research please tick (√) here______
Please sign your name here________________________________
How can I contact you e.g. phone number, at day centre, etc.
Home phone number ☎__________ Other phone number☎__________
Thank you.

5.5. *Appendix Five: Consent Form (men):*

(please tick boxes to say the things below have happened)

I have been given a copy of the information sheet.

I have had the research project explained to me.

I have had any questions I had answered.

I have had time to think about whether I want to take part.

I understand that what I say will be kept private.

I understand that if I change my mind and don't want to take part that is OK.

I understand that my services will not be badly affected as a result of taking part.

I would like to help with this research please tick (√) here______

I don't want to help with this research please tick (√) here______

Please sign your name here______________________________
Print name______________________________________

Contact Address______________________________________

____

Date _________________________

5.6. *Appendix Six: Initial themes / nodes*

NVivo revision 2.0.161 Licensee: Paul Wheeler

Project: backup 020604 User: Administrator Date: 17/08/2004 - 12:51:32

NODE LISTING

Nodes in Set: All Tree Nodes

Created: 02/06/2004 - 09:57:35

Modified: 02/06/2004 - 09:57:35

Number of Nodes: 130

1 (1) /socio-sexual education

2 (1 1) /socio-sexual education/sex ed about females

3 (1 2) /socio-sexual education/sex ed informal

4 (1 3) /socio-sexual education/sex ed re conception

5 (1 4) /socio-sexual education/sex ed re consent

6 (1 5) /socio-sexual education/sex ed re contraception & sti

7 (1 6) /socio-sexual education/sex ed re negative things

8 (1 7) /socio-sexual education/sex ed re puberty

9 (1 8) /socio-sexual education/sex ed re relationships

10 (1 9) /socio-sexual education/perceived importance of sex ed

11 (1 10) /socio-sexual education/receipt of sex ed

12 (2) /Occupation & occupational aspiration

13 (2 1) /Occupation & occupational aspiration/job stability

14 (2 2) /Occupation & occupational aspiration/no planned occupation

15 (2 3) /Occupation & occupational aspiration/type of work

16 (2 4) /Occupation & occupational aspiration/desire to change type of work

17 (3) /living arrangements and sense of pla

18 (3 1) /living arrangements and sense of pla/lives with family member

19 (3 1 1) /living arrangements and sense of pla/lives with family member/being allowed to grow up

20 (3 1 2) /living arrangements and sense of pla/lives with family member/taking people to family home

21 (3 1 3) /living arrangements and sense of pla/lives with family member/use of phone

22 (3 1 4) /living arrangements and sense of pla/lives with family member/parental concerns of vulnerability

23 (3 2) /living arrangements and sense of pla/living in supported accommodation

24 (3 2 1) /living arrangements and sense of pla/living in supported accommodation/beliefs re staff control

25 (3 2 2) /living arrangements and sense of pla/living in supported accommodation/taking people home

26 (3 2 3) /living arrangements and sense of pla/living in supported accommodation/phone use

27 (3 2 4) /living arrangements and sense of pla/living in supported accommodation/staff control

28 (3 2 5) /living arrangements and sense of pla/living in supported accommodation/vulnerability in accommodation

29 (3 3) /living arrangements and sense of pla/experience in residential care

30 (3 4) /living arrangements and sense of pla/preferred living arrangements

31 (3 5) /living arrangements and sense of pla/lives alone

32 (3 5 1) /living arrangements and sense of pla/lives alone/use of phone

33 (3 5 2) /living arrangements and sense of pla/lives alone/level of support

34 (3 5 3) /living arrangements and sense of pla/lives alone/taking people home

35 (3 5 4) /living arrangements and sense of pla/lives alone/concern re vulnerability

36 (4) /others attitudes to intimate & perso

37 (4 1) /others attitudes to intimate & perso/family attitudes to relationship

38 (4 2) /others attitudes to intimate & perso/others attitudes towards sexual acti

39 (4 3) /others attitudes to intimate & perso/support staff attitudes to relations

40 (4 4) /others attitudes to intimate & perso/others attitudes to girlfriend

41 (4 5) /others attitudes to intimate & perso/taking girlfriends home

42 (4 6) /others attitudes to intimate & perso/concerns re homophobia

43 (5) /Finances and sense of agency

44 (5 1) /Finances and sense of agency/control over finances

45 (5 2) /Finances and sense of agency/desire for more money

46 (5 3) /Finances and sense of agency/payment for work

47 (5 4) /Finances and sense of agency/effect of limited finances

48 (5 5) /Finances and sense of agency/finances

49 (5 6) /Finances and sense of agency/viewed as child

50 (5 7) /Finances and sense of agency/parental control over money
51 (6) /Community participation
52 (6 1) /Community participation/control over leisure
53 (6 2) /Community participation/leisure time
54 (6 3) /Community participation/IT skills~access
55 (6 4) /Community participation/support to access leisure
56 (6 5) /Community participation/transport
57 (6 6) /Community participation/opportunities for meeting people
58 (6 7) /Community participation/perceived value of voluntary orgs
59 (9) /sexuality~ attitudes & behaviour
60 (9 1) /sexuality~ attitudes & behaviour/condom use
61 (9 2) /sexuality~ attitudes & behaviour/attitudes to sexual acts
62 (9 3) /sexuality~ attitudes & behaviour/attitude to & use of pornography
63 (9 4) /sexuality~ attitudes & behaviour/sexual experiences
64 (9 5) /sexuality~ attitudes & behaviour/perceived control over sexuality
65 (9 6) /sexuality~ attitudes & behaviour/sexual being
66 (9 7) /sexuality~ attitudes & behaviour/feelings about sex
67 (10) /Sense of self
68 (10 1) /Sense of self/attempt to change body image
69 (10 2) /Sense of self/body image
70 (10 3) /Sense of self/desire to change body image
71 (10 4) /Sense of self/transgender
72 (10 5) /Sense of self/desire for compliments
73 (10 6) /Sense of self/perceived ability to satisfy sexuall
74 (10 7) /Sense of self/perception of non ld men
75 (10 8) /Sense of self/desire to change personality
76 (10 9) /Sense of self/self perception ~ percept as differe
77 (10 10) /Sense of self/attempt to change personality
78 (10 11) /Sense of self/self perception
79 (11) /understanding of issues around sexua
80 (11 1) /understanding of issues around sexua/understanding about law and sex
81 (11 2) /understanding of issues around sexua/understanding about STIs
82 (11 3) /understanding of issues around sexua/understanding contraception
83 (11 4) /understanding of issues around sexua/understanding of consent
84 (11 5) /understanding of issues around sexua/understanding of pornography

85 (11 7) /understanding of issues around sexua/importance of consent
86 (11 8) /understanding of issues around sexua/perception of sex as danger
87 (11 9) /understanding of issues around sexua/meaning of sex
88 (11 10) /understanding of issues around sexua/meaning of attractive
89 (11 11) /understanding of issues around sexua/meaning of love
90 (12) /The context of parenting by mwld
91 (12 1) /The context of parenting by mwld/parenting knowledge
92 (12 2) /The context of parenting by mwld/parenting role
93 (12 3) /The context of parenting by mwld/desire to parent
94 (12 4) /The context of parenting by mwld/support for parenting
95 (12 5) /The context of parenting by mwld/Others attitudes to pwld parenting
96 (12 6) /The context of parenting by mwld/views on children
97 (12 7) /The context of parenting by mwld/family planning
98 (13) /Understanding others through being m
99 (13 3) /Understanding others through being m/attitude to people with physical dis
100 (13 4) /Understanding others through being m/attitudes to gay relationships
101 (13 7) /Understanding others through being m/attitude to women
102 (13 7 1) /Understanding others through being m/attitude to women/attitude to lesbians
103 (13 7 2) /Understanding others through being m/attitude to women/perceived role in contraception
104 (13 7 5) /Understanding others through being m/attitude to women/attitude to women with LD
105 (13 7 6) /Understanding others through being m/attitude to women/division of labour
106 (14) /Experience of & attitudes towards in
107 (14 1) /Experience of & attitudes towards in/desire for girlfriend
108 (14 2) /Experience of & attitudes towards in/desired attributes of girlfriend
109 (14 3) /Experience of & attitudes towards in/difference between girlfriend and ot
110 (14 4) /Experience of & attitudes towards in/having a girlfriend
111 (14 5) /Experience of & attitudes towards in/where met girlfriend
112 (14 6) /Experience of & attitudes towards in/duration of relationship with girlfr

113 (14 7) /Experience of & attitudes towards in/privacy ~ opps for sex activity

114 (14 8) /Experience of & attitudes towards in/perceive need for support in relatio

115 (14 9) /Experience of & attitudes towards in/right to relationships

116 (14 10) /Experience of & attitudes towards in/marriage

117 (14 11) /Experience of & attitudes towards in/someone to talk to about relationshi

118 (14 12) /Experience of & attitudes towards in/things done with girlfriend

119 (14 13) /Experience of & attitudes towards in/fear of rejection

120 (14 14) /Experience of & attitudes towards in/impact of parental breakup

121 (15) /Attitudes to and experience of plato

122 (15 1) /Attitudes to and experience of plato/friendships

123 (15 2) /Attitudes to and experience of plato/important things in relationships

124 (15 3) /Attitudes to and experience of plato/opportunities for developing friends

125 (16) /Personal experience of bullying and

126 (16 1) /Personal experience of bullying and/Bullying disability related

127 (16 1 1) /Personal experience of bullying and/Bullying disability related/support re bullying

128 (16 2) /Personal experience of bullying and/experience of sexual abuse

129 (16 2 1) /Personal experience of bullying and/experience of sexual abuse/support re abuse

130 (16 3) /Personal experience of bullying and/attitudes of others with ld to ld

5.7. *Appendix Seven: Summary of recommendations*

5.7.1. Recommendations for practice:

- Service providers and carers need to work in a manner that assists men with learning disabilities to become more confident and competent in decision making. This requires a move from a paternalistic, dependency inducing approach to one of facilitation where carers and clients work in alliance with one another.
- There is a need for greater resources to be made available for independent inexpensive advice, such as advocacy services.
- Services should provide training that increases the chances of men with learning disabilities obtaining employment.
- Services should provide men with learning disabilities with increased support in accessing and participating in their communities.
- Services should work to improve the self-esteem and body-image of men with learning disabilities, for example by using cognitive behavioural therapies, and addressing power imbalances between carers and their clients.
- Services should work to promote independence and autonomy in men with learning disabilities whilst at the same time challenging notions of the 'ideal male'
- Services should ensure they have policies in place that recognise diversity and promote equality. These should be accessible to staff and service users and appropriate training should be provided on these issues.
- Services should ensure that discrimination is addressed in a manner that both clearly signals its unacceptability and which ensures that the person discriminated against receives appropriate support.
- Socio-sexual education should be broader than it generally is at present. It should include such things as discussion of possible reasons why one might engage in sexual activity, emotional aspects of relationships, women's bodies, and activities additional to penetrative intercourse. Whilst there is a need to discuss such things as abuse, pregnancy and sexually transmitted infections, the overall emphasis should not be negatively biased. Rather a balanced view should be presented.

- Socio-sexual education should accurate and accessible and should be appropriate to the needs of the individual. It should be provided throughout the person's life time.
- Services should provide training for potential peer educators who may provide men with a learning disability with education and support that is complementary to professional socio-sexual education.
- Services should train staff to act as specialists in socio-sexual issues. These staff may then work both with individuals or groups of men with learning disabilities and with staff.
- Staff should be encouraged to address any inaccurate information, or unacceptable attitudes such as racism, sexism and homophobia that may be portrayed in popular television programmes and magazines.
- Services should ensure that staff and service users have a knowledge and understanding of the law appertaining to sexual behaviour and issues such as consent.
- There should be greater inclusion of sexuality in the content of syllabi of those training to become professional carers such as nurses and social workers.
- Services should provide greater support to formal and informal carers as to how they might better respond to the sexuality of those they care for.
- Services should ensure that policies relating to bullying or abuse are accessible and that they are implemented.

5.7.2. Recommendations for policy change:

- When new legislation and policy is introduced, care must be taken to ensure adequate funding is available to meet needs resulting from such changes. For example, the Mental Capacity Bill, if enacted, will increase the need for access to advocacy services.
- Greater emphasis should be placed on supporting men with learning disabilities in employment than is currently the situation.
- The current 'benefits trap' and regulations relating to 'therapeutic employment' needs reviewing and addressing in order that men with learning disabilities gain a financial advantage from employment.

Alternatively, higher state benefits should be provided and there should be a simplification and expansion of the direct payments scheme.

- Policies relating to risk assessment should emphasise the appropriateness of supporting men with learning disabilities to express their sexuality in an appropriate and safe way rather than preventing them from expressing their sexuality.
- Policies should recognise diversity and promote equality. Such policies need to exist at both national and local levels.
- The writers, producers and publishers of television programmes and magazines should be encouraged to deal with issues relating to sexuality in an accurate and sensitive manner. This should reflect appropriate legislation appertaining to sexual behaviour and to anti-discrimination.
- Central government should provide accessible guidance in relation to legislation appertaining to sexual behaviour and complex issues such as consent.
- There is need for a nationwide open debate about the use of genetic testing and its implications for men with a learning disability.
- National and local policies should be produced concerning the issue of bullying, methods of prevention and appropriate responses.

5.7.3. Recommendations for further research:

- Research should be conducted into the relationship between low self-esteem and negative body-image and ways of addressing such a relationship.
- Further research should be conducted into the way that men with learning disabilities understand others and difference, whether this differs greatly to the majority population and how such attitudes might be improved.
- Research should be conducted across a variety of types of respondent in order to determine factors that affect people's attitudes towards supporting, or otherwise, the expression of sexuality by men with learning disabilities.
- Research should be undertaken to ascertain the extent to which attitudes influence carers support or otherwise of the expression of sexuality by men with learning disabilities.

Bibliography:

(2000). In re A (Male sterilisation). Sweet & Maxwell Limited, England and Wales Court of Appeal, Family Division. **[2000]1 F.L.R. 549.**

Abramson, P. R., T. Parker, et al. (1988). "Sexual expression of mentally retarded people." American Journal on Mental Retardation **93**(3): 328-334.

Adams, G. L., R. J. Tallon, et al. (1982). "Attitudes toward the sexuality of mentally retarded and non-retarded persons." Education and Training of the Mentally Retarded **17**: 307-312.

Adams, M. (1971). Mental retardation and its social dimensions. New York, Columbia University Press.

Adcock, K. and G. Stanley (1996). Sexual health education and children and young people with learning disabilities: A practical way of working for professionals, parents and carers. Kidderminster, Worcs., BILD / Barnardos.

Alderson, P. (2001). "Down's syndrome: cost, quality and value of life." Social Science and Medicine **53**: 627-638.

Allington, C. L. J. (1992). "Sexual abuse within services for people with learning disabilities." Mental Handicap **20**(2): 59-63.

Altheide, D. L. and J. M. Johnson (1998). Criteria for assessing interpretative validity in qualitative research. Collecting and interpreting qualitative materials. N. Denzin and Y. Lincoln. London, Sage: 283-312.

Ambalu, S. (1997). Communication. Adults with learning disabilities: A practical approach for health professionals. J. O'Hara and A. Serlinger. Chichester, John Wiley & Sons: 45-60.

Ames, T.-R. H. and P. Samowitz (1995). "Inclusionary standard for determining sexual consent for individuals with developmental disabilities." Mental Retardation **33**(4): 264-268.

Andrews, J. (1996). Identifying and providing for the mentally disabled in early modern London. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Andron, L. and M. L. Sturm (1973). "Is 'I do' in the repertoire of the retarded? A study of the functioning of married retarded couples." Mental Retardation **11**(1): 31-4.

Anonymous (1997). More than 1,000 Australian girls illegally sterilized. Women's Health Weekly. **22/12/97-29/12/97:** 6-7.

Antaki, C. and M. Rapley (1996). "Questions and answers to psychological assessment schedules: hidden troubles in 'quality of life' interviews." Journal of Intellectual Disability Research **40**(5): 421-437.

Antaki, C., N. Young, et al. (2002). "Shaping clients' answers: departures from neutrality in care-staff interviews with people with a learning disability." Disability and Society **17**(4): 435-455.

Antonak, R. F., J. A. Mulick, et al. (1995). "Influence of mental retardation severity and respondent characteristics on self-reported attitudes toward mental retardation and eugenics." Journal of Intellectual Disability Research **39**(4): 316-325.

Archer, J. and V. Rhodes (1987). "Bereavement and reactions to job loss: a comparative review." British Journal of Social Psychology **26**(3): 211-224.

Atkins, S. and B. Hoggett (1984). Women and the Law. Oxford, Basil Blackwell.

Atkinson, D. (1988). "Research interviews with people with mental handicaps." Mental Handicap Research **1**(1): 75-90.

Atkinson, D. and J. Walmsley (1999). "Using autobiographical approaches with people with learning disabilities." Disability and Society **14**(2): 203-216.

Atkinson, P. A. (1992). Understanding ethnographic texts. London, Sage.

Aunos, M. and M. A. Feldman (2002). "Attitudes towards sexuality, sterilisation, and parenting rights of persons with intellectual disabilities." Journal of Applied Research in Intellectual Disabilities **15**(4): 285-296.

Aylott, J. (1999). "Is the sexuality of people with a learning disability being denied?" British Journal of Nursing **8**(7): 438-442.

Bailey, A., O. Barr, et al. (2001). "Police attitudes toward people with intellectual disability: an evaluation of awareness training." Journal of Intellectual Disability Research **45**(4): 344-350.

Bambrick, M. and G. E. Roberts (1991). "The sterilisation of people with a mental handicap: the views of parents." Journal of Mental Deficiency Research **35**: 353-363.

Bancroft, J. (1989). Human sexuality and its problems. Edinburgh, Churchill Livingstone.

Banister, P., E. Burman, et al. (1994). Qualitative methods in psychology: A research guide. Buckingham, Open University Press.

Barker, C., N. Pistrang, et al. (2002). Research methods in clinical psychology. Chichester, John Wiley & Sons.

Baroff, G. S. and J. G. Olley (1999). Mental retardation: nature, cause and management. Philadelphia, Brunner/Mazel (Taylor & Francis).

Barr, O. (1995). "Normalisation: what it means in practice." British Journal of Nursing 4(2): 90-94.

Bartlett, P. and R. Sandland (2000). Mental health law; policy and practice. London, Blackstone Press.

Bartlett, P. and D. Wright (1999). Community Care and its antecedents. Outside the walls of the asylum: The history of care in the community, 1750-2000. P. Bartlett and D. Wright. London, Athlone Press: 1-18.

Bass, M. S. (1963). "Marriage, parenthood and prevention of pregnancy." American Journal of Mental Deficiency **68**(3): 318-333.

Battacharyya, G. (2002). Sexuality and society. London, Routledge.

Beail, N. (2002). "Interrogative suggestibility, memory and intellectual disability." Journal of Applied Research in Intellectual Disabilities **15**: 129-137.

Behi, R. and E. Edwards-Behi (1987). "Sexuality and mental handicap." Nursing Times **83**(43): 50-53.

Bell, D. M. (2001). "The place of sexual counselling and sex therapy for men and women with intellectual disabilities - the value of a two stage approach." Working with people who have a Learning Disability **17**(4): 12-19.

Berger, P. and T. Luckman (1966). The social construction of reality. London, Penguin.

Beyer, S., L. Goodere, et al. (1997). The costs and benefits of supported employment. London, HMSO.

Beynon, J. (2002). Masculinities and culture. Buckingham, Open University Press.

Biklen, S. K. and C. R. Moseley (1988). ""Are you retarded?" "No, I'm Catholic": Qualitative methods in the study of people with severe handicaps." JASH **13**(3): 155-162.

Blackburn, M. (1995). "Sexuality, disability and abuse: advice for life...not just for kids!" Child: Care, Health and Development **21**(5): 351-361.

Blackburn, M. (2002). Sexuality & Disability. Oxford, Butterworth-Heinemannn.

Blacker, C. P. (1950). Eugenics in retrospect and prospect, The Galton lecture 1945. London, The Eugenics Society & Cassell & Co.

Blacker, C. P. (1952). Eugenics, Galton and after. London, Gerald Duckworth.

Blacker, C. P. (1961). "Voluntary sterilization: The last sixty years." Eugenics Review **53**(3): 145-7.

Blacker, C. P. (1962). "Voluntary sterilization: The last sixty years." Eugenics Review **54**(1): 9-23.

Blacker, C. P. (1962a). "Voluntary sterilization: Transitions throughout the world." Eugenics Review **54**(3): 143-162.

Blakey, V., J. Frankland, et al. (1996). "Sex education workshops for parents of children with learning disabilities." British Journal of Learning Disabilities **24**: 150-153.

Block, P. (2000). "Sexuality, fertility, and danger: twentieth-century images of women with cognitive disabilities." Sexuality and Disability **18**(4): 239-254.

Block, P. (2002). Sterilisation and sexual control. Health of Women with learning disabilities. P. Walsh, & Heller. Oxford Blackwells: 76 - 89.

Bohner, G. and M. Wanke (2002). Attitudes and attitude change. Hove, East Sussex, Psychology Press.

Booth, T. and W. Booth (1994). "The use of depth interviewing with vulnerable subjects: Lessons from a research study of parents with learning difficulties." Soc. Sci. Med. **39**(3): 415-424.

Booth, T. and W. Booth (1996). "Sounds of silence: Narrative research with inarticulate subjects." Disability and Society **11**(1): 55-69.

Bowler, P. J. (1993). Biology and social thought: 1850-1914. Berkeley, C.A., Office for history of science and technology, University of California.

Boyatzis, R. E. (1998). Transforming qualitative information: Thematic analysis and code development. London, Sage.

Braddock, D. (1988). Challenges in community integration. Integration of developmentally disabled individuals into the community. L. W. Heal, J. I. Haney and A. R. Novak-Amado. Baltimore, Paul H. Brookes: 1-17.

Bradley, K. (2002). Vulnerable Witnesses: A Police Service Guide. London, Home Office.

Brady, S. M. (2001). "Sterilization of girls with intellectual disabilities: past and present justifications." Violence Against Women **7**(4): 432-461.

Brantlinger, E. (1983). "Measuring variation and change in attitudes of residential care staff towards the sexuality of mentally retarded persons." Mental Retardation **21**(1): 17-22.

Brechin, A. and J. Swain (1987). Changing relationships: shared action planning with people with a mental handicap. London, Harper and Row.

Brechin, A. and J. Swain (1988). "Professional / client relationships: Creating a 'working alliance' with people with learning difficulties." Disability, Handicap & Society **3**(3): 213-226.

Bromfield, R., J. R. Weisz, et al. (1986). "Children's judgments and attributions in response to the 'Mentally Retarded' label: A developmnetal approach." Journal of Abnormal Psychology **95**(1): 81-87.

Brown, H. (1994). "An ordinary life?: a review of the normalisation principle as it applies to the sexual options of people with learning disabilities." Disability and Society **9**(2): 123-144.

Brown, H. (1996). "Ordinary women: Issues for women with learning disabilities, A keynote review." British Journal of Learning Disabilities **24**: 47-51.

Brown, H. (1997). Vulnerability issues. Adults with learning disabilities: A practical approach for health professionals. J. O'Hara, & Sperlinger, A. Chichester, John Wiley & Sons: 155-170.

Brown, H. and H. Smith (1989). "Whose 'ordinary life' is it anyway?" Disability, Handicap & Society **4**(2): 105-119.

Brown, H. and H. Smith (1992). Assertion, not assimilation: A feminist perspective on the normalisation principle. Normalisation: a reader for the nineties. H. Brown, & Smith, H. London, Routledge: 149-171.

Brown, H., J. Stein, et al. (1995). "The sexual abuse of adults with learning disabilities: report of a second two year incidence survey." Mental Handicap Research **8**(1): 3-24.

Brown, H. and D. Thompson (1997). "The ethics of research with men who have learning disabilities and abusive sexual behaviour: a minefield in a vacuum." Disability and Society **12**(5): 695-707.

Brown, H. and V. Turk (1992). "Defining sexual abuse as it affects adults with learning disabilities." Mental Handicap **20**(2): 56-58.

Burns, J. (2000). "Gender identity and women with learning disabilities: The third sex." Clinical Psychology Forum(137): 11-15.

Burr, V. (2003). Social constructionism. London, Routledge.

Burt, C. (1952). Intelligence and fertility: The effect of the differential birthrate on inborn mental characteristics. London, The Eugenics Society & Cassell & Co., Ltd.

Burton, L., I. Valenti, et al. (2000). TARGET - focusing on the sexual and emotional needs of people with learning disabilities. London, FPA: 22.

Butler Committee (1975). Report of the committee on mentally abnormal offenders. London, HMSO.

Butler, J. (1999). "Revisiting bodies and pleasures." Theory, Culture and Society **16**(2): 11 - 20.

Buunk, B. P. (2001). Affiliation, attraction and close relationships. Introduction to Social Psychology. M. Hewstone and W. Stroebe. Oxford, Blackwell: 371 - 400.

Callaghan, P. and J. Morrisey (1993). "Social support and health: a review." Journal of Advanced Nursing **18**: 203 - 210.

Cambridge, P. (1996). "Assessing and meeting needs in HIV and learning disability." British Journal of Learning Disabilities **24**: 52-57.

Cambridge, P. (1997a). "How far to gay? The politics of HIV in learning disability." Disability and Society **12**(3): 427-453.

Cammack, J. S. (1938). Moral problems of mental defect. London, Burns, Oates & Washbourne Ltd.

Caplan, P. (1987). Introduction. The cultural construction of sexuality. P. Caplan. London, Routledge: 1-30.

Carabine, J. (1995). Invisible sexualities: Sexuality, politics and influencing policy making. A simple matter of justice:Theorizing Lesbian and Gay politics. A. R. Wilson. London, Cassell: 91-109.

Carlson, G., M. Taylor, et al. (2000). "Sterilisation, drugs which supress sexual drive, and young men who have intellectual disability." Journal of Intellectual and Developmental Disability **25**(2): 91-104.

Carnaby, S. (1997). "What do you think? A qualitative approach to evaluating individual planning services." Journal of Intellectual Disability Research **41**(3): 225-231.

Carnaby, S. (2002). The bigger picture: Understanding approaches to learning disability. Learning disability today. S. Carnaby. Brighton, Pavillion: 7-21.

Carnaby, S., Ed. (2002). Learning disability today. Brighton, Pavillion.

Carr, G. (1996). "Themes relating to sexuality that emerged from a discourse analysis of the Nursing Times during 1980-1990." Journal of Advanced Nursing **24**: 196-212.

Carr, L. T. (1991). "Sexuality - a topical issue for nursing." Nursing Standard **6**(1): 52-5.

Carr, L. T. (1995). "Sexuality and people with learning disabilities." British Journal of Nursing **4**(19): 1135-1141.

Chadwick, R. (2001). Whose choice? Whose responsibility? Ethical issues in prenatal diagnosis and learning disability. Considered choices? The new genetics, prenatal testing and people with learning disabilities. L. Ward. Kidderminster, BILD: 82-90.

Chapman, E. and J. A. Smith (2002). "Interpretative phenomenological analysis and the new genetics." Journal of Health Psychology **7**(2): 125-130.

Chapman, J. W. and A. S. Pitceathly (1985). "Sexuality and mentally handicapped people: Issues of sex education, marriage, parenthood, and care staff attitudes." Australia and New Zealand Journal of Developmental Disabilities **10**(4): 227-235.

Chapman, K. and P. Oakes (1995). "Asking people with learning disabilities their view on direct psychological interventions." Clinical Psychology Forum **July 1995**: 28-33.

Chappell, A. L. (1992). "Towards a sociological critique of the normalisation principle." Disability, Handicap & Society **7**(1): 35-51.

Chappell, A. L. (1994). "A question of friendship: community care and the relationships of people with learning difficulties." Disability and Society 9(4): 419-43.

Charles, N. (2002). Gender in modern Britain. Oxford, Oxford University Press.

Charmaz, K. (1995). Grounded theory. Rethinking methods in psychology. J. A. Smith, R. Harre and L. v. Langenhove. London, Sage: 27-49.

Charmaz, K. (2003). Grounded theory. Qualitative psychology: A practical guide to research methods. J. A. Smith. London, Sage: 81-110.

Chivers, J. and S. Mathieson (2000). "Training in sexuality and relationships: An Australian model." Sexuality and Disability 18(1): 73-80.

Christian, L. A., J. Stinson, et al. (2001). "Staff values regarding the sexual expression of women with developmental disabilities." Sexuality and Disability 19(4): 283-291.

Clare, I. C. H. and G. H. Gudjonsson (1993). "Interrogative suggestibility, confabulation, and acquiescence in people with mild learning disabilities (mental handicap): Implications for reliability during police interrogations." British Journal of Clinical Psychology 32: 295-301.

Clarke, D. (1986). Mentally handicapped people: living and learning. London, Bailliere Tindall.

Clements, J., I. Clare, et al. (1995). "Real men, real women, real lives? Gender issues in learning disabilities and challenging behaviour." Disability and Society 10(4): 425-435.

Cocks, E. and J. Cockram (1995). "The participatory research paradigm and intellectual disability." Mental Handicap Research 8(1): 25-37.

Coleman, E. M. and W. D. Murphy (1980). "A survey of sexual attitudes and sex education programs among facilities for the mentally retarded." Applied Research in Mental Retardation 1: 269-276.

Collier, R. (1995). Masculinity, law and the family. London, Routledge.

Collins, G. J. and D. Cozens (1999). "Sexuality and personal relationships for people with learning disabilities: a framework for assessment and intervention." Journal of learning Disabilities for Nursing, Health and Social Care 3(3): 130-135.

Committee On Homosexual Offences And Prostitution. (1957). The report of the committee on homosexual offences and prostitution, (the Wolfenden Report). London, HMSO, Cmnd. 247.

Corbett, J. (1994). "A proud label: exploring the relationship between disability politics and gay pride." Disability and Society 9(3): 343-357.

Cox, P. (1996). Girls, deficiency and delinquency. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Craft, A. and H. Brown (1994). Personal relationships and sexuality: the staff role. Practice issues in sexuality and learning disabilities. A. Craft. London, Routledge: 1-22.

Craft, A. and M. Craft (1979). Personal relationships and partnerships for the mentally handicapped. Tredgold's mental retardation. M. Craft. London, Bailliere Tindall: 354-371.

Craft, A. and M. Craft (1981). "Sexuality and mental handicap: A review." British Journal of Psychiatry **(1181) 139**: 494-505.

Craft, A. and M. Craft, Eds. (1983). Sex education and counselling for mentally handicapped people. Tunbridge Wells, Costello.

Craft, A. and M. Craft (1985). Sexuality and personal relationships. Mental handicap: A multi-disciplinary approach. M. Craft, Bicknell, J., & Hollins, S. London, Bailliere Tindall: 177-196.

Craft, M. and A. Craft (1978). Sex and the mentally handicapped. London, Routledge and Kegan Paul.

Criminal Law Revision Committee. (1980). Criminal Law Revision Committee working paper - Sexual Offences. London, HMSO.

Criminal Law Revision Committee. (1984). Criminal Law Revision Committee 15th Report; Sexual Offences. London, HMSO, Cmnd. 9213.

Dalley, G. (1992). Social welfare ideologies and normalisation: links and conflicts. Normalisation: a reader for the nineties. H. Brown, & Smith, H. London, Routledge: 100-111.

Daniluk, J. C. (1998). Women's sexuality across the lifespan: Challenging myths, creating meanings. The Guilford Press.

Davidson-Paine, C. and J. Corbett (1995). "A double coming out: Gay men with learning disabilities." British Journal of Learning Disabilities **23**: 147-151.

Davies, C. H. and R. Jenkins (1997). "She has different fits to me: how people with learning disabilities see themselves." Disability and Society **12**(1): 95-109.

Dawson, G. (1993). The opinions and attitudes of parents on the sexuality of their sons or daughters with learning disabilities, Unpublished MSc (Econ.) thesis. Centre for applied social studies. Swansea, University of Wales, Swansea College.

Day, M. and B. Harry (1999). "'Best Friends': The construction of a teenage friendship." Mental Retardation **37**(3): 221-231.

Deeley, S. (2002). "Professional ideology and learning disability: an analysis of internal conflict." Disability and Society **17**(1): 19-33.

Dennis, K. J. (1975). Abortion, babies and contraception: The A, B, C of eugenics. Southampton, University of Southampton.

Department of Health (2000). No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. London, Department of Health and The Home Office.

Department of Health (2001). Valuing People: A new strategy for learning disability for the 21st century. London, HMSO.

Department of Health (2001a). The National Health Strategy for Sexual Health and HIV. London, HMSO.

Department of Health and Social Services and the Welsh Office (1971). Better Services for the mentally handicapped. Cmnd 4683. London, HMSO.

Digby, A. (1996). Contexts and perspectives. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Diversi, M. (2003). Glimpses of street children: through short stories. Social construction: a reader. M. Gergen and K. J. Gergen. London, Sage: 109-118.

Dixon, H. (1988). Sexuality and mental handicap: an educators resource book. Wisbech, Cambs., Learning Development Aids.

Dorney, M. (1999). "Group work with women with learning disabilities." British Journal of Learning Disabilities 27: 132-135.

Dowbriggen, I. R. (1997). Keeping America sane: Psychiatry and eugenics in the United States and Canada, 1880-1940. New York, Cornell University Press.

Downs, C. (1998). Sexuality: Challenges and dilemmas. People with profound and multiple learning disabilities: A collaborative approach to meeting complex needs. P. Lacey, & Ouvry,C. London, David Fulton: 76-87.

Downs, C. and A. Craft (1996). "Sexuality and profound and multiple impairment." Tizard Learning Disability Review 1(4): 17-22.

Drouard, A. (1998). Eugenics in France and in Scandinavia: Two case studies. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute.

Dugdale, R. L. (1877). The Jukes: A study in crime, pauperism, disease and heredity. New York, Putnam.

Edgerton, R. B. (1993). The cloak of competence: revised and updated. Berkeley, L.A., University of California Press.

Edmonds, C. and A. Collins (1999). "Using social and educational approaches to enable a man with learning disabilities to develop his sexual identity and orientation." British Journal of Learning Disabilities 27: 127-131.

Edmondson, B., K. McCombs, et al. (1979). "What retarded adults believe about sex." American Journal of Mental Deficiency 84(1): 11-18.

Edmondson, B. and J. Wish (1975). "Sex knowledge and attitudes of moderately retarded males." American Journal of Mental Deficiency 80(2): 175-179.

Ehlers-Flint, M. L. (2002). "Parenting perceptions and social supports of mothers with cognitive disabilites." Sexuality and Disability **20**(1): 29-51.

Ekdawi, I., S. Gibbons, et al. (2000). Whose reality is it anyway? Putting social constructionist philosophy into everyday clinical practice. Brighton, Pavilion.

Emerson, E. (1992). What is normalisation? Normalisation a reader for the nineties. H. Brown, & Smith, H. London, Routledge: 1-18.

Epstein, S. (2002). A Queer encounter: Sociology and the study of sexuality. Sexuality and Gender. L. W. Christine and A. Stein. Oxford, Blackwell: 44-59.

Estabrook, A. H. (1916). The Jukes in 1915. Washington, Carnegie Institute.

Fairburn, G., D. Rowley, et al. (1995). Sexuality, learning difficulties and doing what's right. London, David Fulton.

Farber, B. (1968). Mental retardation; its social context and social consequences. Boston, Houghton Mifflin.

Feldman, M. A. (1994). "Parenting education for parents with intellectual disabilities: A review of outcome studies." Research in Developmental Disabilities **15**(4): 299-332.

Finlay, W. M. L. and E. Lyons (2002). "Acquiescence in interviews with people who have mental retardation." Mental Retardation **40**(1): 14-29.

Fischer, H. L. and M. J. Krajicek (1974). "Sexual development of the moderately retarded child: Level of information and parental attitudes." Mental Retardation **12**(3): 28-30.

Fletcher, A. (2001). Three generations of imbeciles are enough: eugenics, the new genetics and people with learning dificulties. Considered choices? The new genetics, prenatal testing and people with learning disabilities. L. Ward. Kidderminster, BILD: 72-81.

Flick, U. (2002). An introduction to qualitative research. London, Sage.

Flowers, P., J. A. Smith, et al. (1997). "Health and romance: Understanding unprotected sex in relationships between gay men." British Journal of Health Psychology **2**: 73-86.

Flynn, M. C. (1986). "Adults who are mentally handicapped as consumers: issues and guidelines for interviewing." Journal of Mental Deficiency Research **30**: 369-377.

Flynn, M. C. and J. K. Salem (1986). "Adults who are mentally handicapped and living with their parents: Satisfaction and perceptions regrding their lives and circumstances." Journal of Mental Deficiency Research **30**: 379-387.

Flynn, R. J. and R. A. Lemay, Eds. (1999). A quarter-century of normalization and social role valorization: Evolution and impact. Ottawa, Ontario, University of Ottawa Press.

Foucault, M. (1963). The birth of the clinic: An archeology of medical perception. London, Routledge.

Foucault, M. (1975). Discipline and punish: The birth of the prison. London, Penguin.

Foucault, M. (1979). The history of sexuality, volume 1 - an introduction. London, Allen Lane.

Foucault, M. (1984). The history of sexuality, volume 2 - the use of pleasure. London, Viking Penguin.

Foucault, M. (1984a). The history of sexuality, volume 3 - the care of the self. London, Penguin.

Fox, R. W. (1978). So far disordered in mind - insanity in California, 1870-1930. Berkeley, C.A., University of California Press.

Fraser, M. and A. Fraser (2001). "Are people with learning disabilities able to contribute to focus groups on health promotion?" Journal of Advanced Nursing **33**(2): 225-233.

Fraser, W., D. Sines, et al., Eds. (1998). Hallas' The care of people with intellectual disabilities. Oxford, Butterworth-Heinemann.

Gagnon, J. H. (1977). Human sexualities. Glenview, Illinois, Scott, Foresman & Co.

Gagnon, J. H. and R. G. Parker (1995). Conceiving sexuality. Conceiving sexuality: approaches to sex research in a postmodern world. R. G. Parker, & Gagnon, J.H. London, Routledge: 3 - 16.

Galton, F. (1901). The possible improvement of the human breed, under the existing conditions of law and sentiment - 2nd Huxley Lecture of the Anthropological Society, delivered October 29, 1901. Essays in eugenics. F. Galton. London, The Eugenics Education Society: 1-34.

Galton, F. (1904). Eugenics: its definition, scope and aims. Read before the Sociological Society at the School of Economics and Political Science, London University, May 16, 1904. Essays in eugenics. F. Galton. London, The Eugenics Education Society: 35-43.

Galton, F. (1905). Restrictions in Marriage. Paper given at the Sociological Society at the School of Economics and Political Science, London University, February 14, 1905. Essays in eugenics. F. Galton. London, The Eugenics Education Society: 44-59.

Galton, F. (1905a). Studies in National Eugenics. Paper given at the Sociological Society at the School of Economics and Political Science, London University, February 14, 1905. Essays in eugenics. F. Galton. London, The Eugenics Education Society: 44-59.

Galton, F. (1905b). Eugenics as a factor in Religion. Paper given at the Sociological Society at the School of Economics and Political Science, London

University, February 14, 1905. Essays in eugenics. F. Galton. London, The Eugenics Education Society: 68-74.

Gamson, J. (1995). "Must identity movements self-destruct? A queer dilemma." Social Problems **42**(3): 390-407.

Geertz, C. (1975). The interpretation of cultures: a collection of essays. London, Hutchinson.

Gelb, S. A. (1987). "Social deviance and the 'discovery' of the moron." Disability, Handicap & Society **2**(3): 247-258.

Gergen, K. J. (2003). Knowledge as socially constructed. Social construction: A reader. M. Gergen and K. J. Gergen. London, Sage: 15-17.

Gergen, M. and K. J. Gergen, Eds. (2003). Social construction: a reader. London, Sage.

Giami, A. (1987). "Coping with the sexuality of the disabled: a comparison of the physically disabled and the mentally retarded." International Journal of Rehabilitation Research **10**(1): 41-48.

Gibbons, F. X. and L. G. Sawin (1979). "Evaluations of mentally retarded persons: 'Sympathy' or patronization?" American Journal of Mental Deficiency **84**(2): 124-131.

Gilbert, P. (1985). Mental handicap; a practical guide for social workers. Sutton, Business Press International Ltd.

Gilbert, T. (1993). "Learning disability nursing: from normalisation to materialism - towards a new paradigm." Journal of Advanced Nursing **18**: 1604-1609.

Gint, K. (1991). The sociology of work: An introduction. Oxford, Polity Press.

Giorgi, A. and B. Giorgi (2003). Phenomenology. Qualitative psychology:A practical guide to research methods. J. A. Smith. London, Sage: 25-50.

Gladstone, D. (1996). The changing dynamic of institutional care - the western counties idiot asylum, 1864-1914. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Goddard, H. H. (1912). The Kallikak family: a study in the heredity of feeblemindedness. New York, Macmillan.

Goffman, E. (1962). Asylums. New York, Doubleday.

Goode, E. and N. Ben-Yehuda (1994). Moral panics: the social construction of deviance. Oxford, Blackwell.

Goodey, C. F. (1996). The psychopolitics of learning disability and disability in seventeenth century thought. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Goodman, J. F. (1989). "Does retardation mean dumb? Children's perceptions of the nature, cause and course of mental retardation." The Journal of Special Education **23**(3): 313-329.

Goodman, L., S. Budner, et al. (1971). "The parents' role in sex education for the retarded." Mental Retardation **9**(1): 43-46.

Goring, C. and K. Pearson (1913). The English convict: A Statistical Study. London, HMSO.

Gottleib, J. and L. Corman (1975). "Public attitudes toward mentally retarded children." American Journal of Mental Deficiency **80**(1): 72-80.

Grigg, E. (2002). Post HIV/AIDS: Emergence of a new morality. The challenge of sexuality in health care. H. Heath, & White, I. Oxford, Blackwell Science: 37-50.

Gross, R. (1996). Psychology: The science of mind and behaviour. London, Hodder & Stoughton.

Gunn, M. J. (1996). Sex and the law - a brief guide for staff working with people with learning disabilities. London, FPA.

Haight, S. L. and D. D. Fachting (1986). "Materials for teaching sexuality, love and maturity to high school students with learning disabilities." Journal of Learning Disabilities **19**(6): 344-350.

Hall, J. E. and H. L. Morris (1976). "Sexual knowledge and attitudes of institutionalized and noninstitutionalized retarded adolescents." American Journal of Mental Deficiency **80**(4): 382-387.

Hall, J. E., H. L. Morris, et al. (1973). "Sexual knowledge and attitudes of mentally retarded adolescents." American Journal of Mental Deficiency **77**(6): 706-709.

Hall, L. A. (1998). Women, feminism and eugenics. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute: 36-51.

Hawkins, M. (1997). Social Darwinism in European and American thought, 1860-1945 - Nature as model and nature as threat. Cambridge, Cambridge University Press.

Haywood, C. and M. M. a. Ghaill (2003). Men and masculinities: Theory, research and social practice. Buckingham, Open University Press.

Heal, L. W. and C. K. Sigelman (1995). "Response biases in interviews of individuals with limited mental ability." Journal of Intellectual Disability Research **39**(4): 331-340.

Heath, H. (2002). The sexual revolution. The challenge of sexuality in health care. I. White and H. Heath. Oxford, Blackwell Science: 25-36.

Heath, H. and I. White, Eds. (2002). The challenge of sexuality in health care. Oxford, Blackwell Science.

Heaton-Ward, W. A. (1977). Left behind - a study of mental handicap. Plymouth, Macdonald & Evans.

Henwood, K. and N. Pidgeon (1994). "Beyond the qualitative paradigm: A framework for introducing diversity within qualitative psychology." Journal of Community & Applied Social Psychology **4**: 225-238.

Hepper, F. (1999). "'A woman's heaven is at her husband's feet'? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability." Journal of Intellectual Disability Research **43**(6): 558-561.

Heshusius, L. (1982). "Sexuality, intimacy, and persons we label mentally retarded: What they think - What we think." Mental Retardation **20**(4): 164-168.

Heyman, B. and S. Huckle (1995). "Sexuality as a perceived hazard in the lives of adults with learning difficulties." Disability and Society **10**(2): 139-155.

Hilliard, L. T. and B. H. Kirman (1965). Mental Deficiency. London, Churchill.

Hingsburger, D. (1993). "Staff attitudes, homosexuality and developmental disability: a minority within a minority." The Canadian Journal of Human Sexuality **2**(1): 19-22.

Hingsburger, D., D. Snell Van Noort, et al. (2000). "But I thought... Sexuality and teens with developmental disabilities." TASH Newsletter(May, 2000): 8-11.

Hogg, J., M. Campbell, et al. (2001). "Evaluation of the effect of an open learning course on staff knowledge and attitudes towards the sexual abuse of adults with learning disabilities." Journal of Applied Research in Intellectual Disabilities **14**: 12-29.

Holden, J. (1998). The final countdown: Alberta approaches a final reckoning on sterilisation claims. Alberta Report. **25**: 10-11.

Holmes, M. (1998). "An evaluation of staff attitudes towards the sexual activity of people with learning disabilities." British Journal of Occupational Therapy. **61**(3): 111-115.

Home Office (1990). Provision for mentally disordered offenders. London, Home Office.

Home Office Crime and Criminal Justice Unit (2002). Criminal Statistics, http://www.homeoffice.gov.uk/rds/pdfs/100years.xls. **7 March 2002.**

Houston, R. A. (1999). 'Not simple boarding'; care of the mentally incapacitated in Scotland during the long eighteenth century. Outside the walls of the asylum. The history of care in the community, 1750-2000. P. Bartlett, & Wright, D. London, Athlone Press: 19-44.

Hoyt, W. D. and L. R. Kogan (2001). "Satisfaction with body image and peer relationships for males and females in a college environment." Sex Roles **45**(3/4): 199-215.

Hunt, A. (1969). *Caring for the severely subnormal*. London, The Spastics Society.

Iredale, R. (2000). "Eugenics and its relevance to contemporary health care." *Nursing Ethics* **7**(3): 205-214.

Jackson, M. (1987). 'Facts of life' or the eroticization of women's oppression? Sexology and the social construction of heterosexuality. *The cultural construction of sexuality*. P. Caplan. London, Routledge: 52 - 81.

Jackson, M. (1996). Institutional provision for the feeble-minded in Edwardian England - Sandlebridge and the scientific morality of permanent care. *From idiocy to mental deficiency*. D. Wright, & Digby, A. London, Routledge.

Jenkins, R. (1989). Barriers to adulthood: long-term unemployment and mental handicap compared. *Making connections: reflecting on the lives and experiences of people with learning difficulties*. A. Brechin, & Walmsley. London, Hodder & Stoughton: 100-108.

Jobling, A., K. B. Moni, et al. (2000). "Understanding friendship: Young adults with Down syndrome exploring relationships." *Journal of Intellectual and Developmental Disability* **25**(3): 235-245.

Johnson, P. R. (1984). Community-based sexuality programs for developmentally handicapped adults. *Proceedings of the sixth congress of the International Association for the Scientific Study of Mental Deficiency: Perspectives and progress in mental retardation*. J. M. Berg. Baltimore, University Park Press. **1: Social, psychological and educational aspects:** 313-321.

Johnson, P. R. (1987). Becoming real: a developmental approach to relationship education. *Mental handicap and sexuality*. A. Craft. Tunbridge Wells, Costello: 62-81.

Johnson, P. R. and R. Davies (1989). "Sexual attitudes of members of staff." *British Journal of Mental Subnormality* **35**(1): 17-21.

Jones, D. C. (2001). "Social comparison and body image: Attractiveness comparisons to models and peers among adolescent girls and boys." *Sex Roles* **45**(9/10): 645-664.

Jones, G. (1980). *Social darwinism and English thought: The interaction between biological and social theory*. Sussex, The Harvester Press.

Jones, G. (1998). Theoretical foundations of eugenics. *Essays in the history of eugenics*. R. A. Peel. London, The Galton Institute: 1-19.

Jones, K. (1960). *Mental health and social policy 1845 -1959*. London, Routledge & Kegan Paul.

Jones, K. (1972). *A history of the mental health services*. London, Routledge & Kegan Paul.

Jordan, B. and G. Dunlap (2001). "Construction of adulthood and disability." *Mental Retardation* **39**(4): 286-296.

Kaeser, F. (1992). "Can people with severe mental retardation consent to mutual sex?" Sexuality and Disability **10**(1): 33-42.

Kanner, I. (1964). A history of the care and study of the mentally retarded. Springfield, Illinois, Charles C. Thomas.

Katoda, H. (1993). "Parents' and teachers praxes of and attitudes to the health and sex education of young people with mental handicaps: a study in Stockholm and Tokyo." Journal of Intellectual Disability Research **37**: 115-129.

Katz, S., T. Shemesh, et al. (2000). "Attitudes of university students towards the sexuality of persons with mental retardation and persons with paraplegia." British Journal of Developmental Disabilities **91**: 109-117.

Kempton, W. (1988). Sex education for persons with disabilities that hinder learning: A teacher's guide. Santa Barbara, CA, James Stanfield Co.

Kempton, W. and E. Kahn (1991). "Sexuality and people with intellectual disabilities." Sexuality and Disability **9**(2): 93-111.

Kerr-Edwards, L. and L. Scott (2003). Talking together about sex and relationships: A practical resource for schools and parents working with young people with learning disabilities. London, Family Planning Association.

Kevles, D. J. (1995). In the name of eugenics: Genetics and the uses of human heredity. Cambridge, Massachusetts, Harvard University Press.

Kevles, D. J. (1998). Eugenics in North America. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute: 208-225.

Keywood, K. (1995). Sterilising the woman with learning difficulties - in her best interests? Law and body politics: Regulating the female body. J. Bridgeman, & Millns, S. Aldershot, Dartmouth: 125-150.

Keywood, K. (2001). "'I'd rather keep him chaste.' Retelling the story of sterilisation, learning disability and (non)sexed embodiment." Feminist Legal Studies **9**: 185-194.

Kimmel, M. S. (1997). Masculinity as homophobia: Fear, shame, and silence in the construction of gender identity. Toward a new psychology of gender: a reader. M. M. Gergen, & Davis, S.N. New York, Routledge: 223 - 242.

Kirman, B. (1975). Mental handicap: a brief guide. London, Crosby Lockwood Staples.

Knifton, C. (1998). "Non-consensual sterilisation of the adult with learning disabilities." British Journal of Nursing 7(19): 1172-1176.

Knox, M. and F. Hickson (2001). "The meanings of close friendship: The views of four people with intellectual disabilities." Journal of Applied Research in Intellectual Disabilities **14**: 276-291.

Koller, R. (2000). "Sexuality and adolescents with autism." Sexuality and Disability **18**(2): 125-135.

Konstantareas, M. M. and Y. J. Lunsky (1997). "Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay." Journal of Autism and Developmental Disorders **27**(4): 1997.

Kroese, B. S., D. Dagnan, et al., Eds. (1997). Cognitive-behaviour therapy for people with learning disabilities. London, Routledge.

Kroese, B. S., A. Gillot, et al. (1998). "Consumers with intellectual disabilities as service evaluators." Journal of Applied Research in Intellectual Disabilities **11**(2): 116-128.

Krouwel, A. and J. W. Duyvendak (2000). The private and the public: Gay and lesbian issues in political science. Lesbian and Gay Studies: An introductory, interdisciplinary approach. T. Sandfort, J. Schuyf, J. W. Duyvendak and J. Weeks. London, Sage: 113-131.

Krueger, R. A. and M. A. Casey (2000). Focus groups: A practical guide for applied research. London, Sage.

Kuna, J. (2001). "The Human Genome Project and Eugenics: Identifying the impact on individuals with mental retardation." Mental Retardation **39**(2): 158-60.

Kvale, S. (1996). Interviews: An introduction to qualitative research interviewing. London, Sage.

Landman, R. (1994). "Making sex safer for people with learning disabilities." Nursing Times **90**(28): 35-37.

Lane, D. (1980). The work needs of mentally handicapped adults. London, Disability Alliance.

Larkin, M. (2003). Interpretative Phenomenological Analysis. 5th Annual IPA Conference, University of Plymouth.

Lawrence, P. and J. Swain (1993). "Sex education for students with severe learning difficulties in further education and the problem of evaluation." Disability, Handicap & Society **8**(4): 405-421.

Leck, G. M. (1995). The politics of adolescent sexual identity and queer responses. The Gay Teen: Educational practice and theory for lesbian, gay and bisexual adolescents. G. Unks. New York, Routledge: 189-200.

Ledbetter, R. (1976). A history of the Malthusian League, 1877-1927. Columbus, Ohio State University Press.

Lee, R. M. (1993). Doing research on sensitive topics. London, Sage.

Lees, S. (1997). Ruling passions: Sexual violence, reputation and the law. Buckingham, Open University Press.

Leiblum, S. R. (1998). Foreword. Women's sexuality across the lifespan: Challenging myths, creating meanings. J. C. Daniluk. New York, The Guilford Press: vi-viii.

Lesseliers, J. (1999). "A right to sexuality." British Journal of Learning Disabilities **27**: 137-140.

Lewis, S. and R. Bor (1994). "Nurses' knowledge of and attitudes towards sexuality and the relationship of these with nursing practice." Journal of Advanced Nursing **20**: 251-259.

Lindsay, W. R., I. Marshall, et al. (1998). "The treatment of men with a learning disability convicted of exhibitionism." Research in Developmental Disabilities **19**(4): 295-316.

Lindsey, M. (1998). Signposts for success in commissioning and providing health services for people with learning disabilities. London, D.o.H.

Lindsey, M. and O. Russell (1999). Once a day. London, NHS Executive: 34.

Llewellyn, G. and D. McConnell (2002). "Mothers with learning difficulties and their support networks." Journal of Intellectual Disability Research **46**(1): 17-34.

Lundstrom-Roche, F. (1982). "Sex roles and mentally handicapped people." Mental Handicap **10**(1): 29-30.

Lunsky, Y. and M. M. Konstantareas (1998). "The attitudes of individuals with autism and mental retardation towards sexuality." Education and Training in Mental Retardation and Developmental Disabilities **33**(1): 24-33.

Maggs-Rapport, F. (2001). "'Best research practice': In pursuit of methodological rigour." Journal of Advanced Nursing **35**(3): 373-383.

Malhotra, S. and B. Mellan (1996). "Cultural and race issues in sexuality work with people with learning difficulties." Tizard Learning Disability Review **1**(4): 7-12.

Manthorpe, J., M. Walsh, et al. (1997). "Issues of risk practice and welfare in learning disability services." Disability and Society **12**(1): 69-82.

March, J., B. Steingold, et al. (1997). "Follow the yellow brick road! People with learning difficulties as co-researchers." British Journal of Learning Disabilities **25**: 77-80.

Maslow, A. (1954). Motivation and personality. New York, Harper and Row.

Matikka, L. M. and H. T. Vesala (1997). "Acquiescence in quality of life interviews with adults who have mental retardation." Mental Retardation **35**(2): 75-82.

Mattinson, J. (1970). Marriage and mental handicap. London, Duckworth.

McCabe, M. P. (1993). "Sex education programs for people with mental retardation." Mental Retardation **31**(6): 377-387.

McCabe, M. P., R. A. Cummins, et al. (1999). "Construction and psychometric properties of sexuality scales: Sex, knowledge, experience and needs scales for people with intellectual disabilities (SexKen-ID), people with physical disabilities (SexKen-PD), and the general population (SexKen-GP)." Research in Developmental Disabilities **20**(4): 241-254.

McCabe, M. P. and A. Schreck (1992). "Before sex education: an evaluation of the sexual knowledge, experience, feelings and needs of people with mild intellectual disabilities." Australia and New Zealand Journal of Developmental Disabilities **18**(2): 75-82.

McCarthy, M. (1993). "Sexual experiences of women with learning disabilities in long-stay hospitals." Sexuality and Disability **11**(4): 277-286.

McCarthy, M. (1998). "Whose body is it anyway? Pressures and control for women with learning disabilities." Disability and Society **13**(4): 557-574.

McCarthy, M. (1998a). "Interviewing people with learning disabilities about sensitive topics: a discussion of ethical issues." British Journal of Learning Disabilities **26**(4): 140-145.

McCarthy, M. (1999). Sexuality and women with learning disabilities. London, Jessica Kingsley Publishing.

McCarthy, M. (2000). Consent, abuse and choices: Women with intellectual disabilities and sexuality. Women with intellectual disabilities: Finding a place in the world. R. Traustadottir, & Johnson, K. London, Jessica Kingsley: 132-156.

McCarthy, M. and D. Thompson (1994). HIV/AIDS and safer sex work with people with learning disabilities. Practice issues in sexuality and learning disabilities. A. Craft. London, Routledge: 186-201.

McCarthy, M. and D. Thompson (1998). Sex and the 3Rs: Rights, responsibilities and risks. Brighton, Pavilion.

McCarthy, M. and D. Thompson (2000). "Becoming a sexual adult." ACT Bulletin(July, 2000): 5-12.

McConkey, R. and D. Ryan (2001). "Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability." Journal of Intellectual Disability Research **45**(1): 83-87.

McDermott, S., M. Martin, et al. (1999). "Program evaluation of a sex education curriculum for women with mental retardation." Research in Developmental Disabilities **20**(2): 93-106.

McGaw, S. (1997). Practical support for parents with learning disabilities. Adults with learning disabilities: A practical approach for health professionals. J. O'Hara and A. Sperlinger. Chichester, Wiley: 123-138.

McGaw, S., K. Ball, et al. (2002). "The effect of group intervention on the relationships of parents with intellectual disabilities." Journal of Applied Research in Intellectual Disabilities **15**(4): 354-366.

McLaren, P. (1995). Moral panic, schooling, and gay identity: Critical pedagogy and the politics of resistance. The Gay Teen: Educational practice and theory for lesbian, gay and bisexual adolescents. G. Unks. New York, Routledge: 105-123.

Mehan, H. (1996). The construction of an LD student: A case study in the politics of representation. Natural Histories of Discourses. M. Silverstein and G. Urban. Chicago, Chicago University Press: 346-363.

Meyen, E. L. and P. M. Retish (1971). "Sex education for the mentally retarded: Influencing teachers' attitudes." Mental Retardation **9**(1): 46-49.

Minkes, J., R. Townsley, et al. (1995). "Having a voice: Involving people with learning disabilities in research." British Journal of Learning Disabilities **23**: 94-97.

Mitchell, L., R. M. Doctor, et al. (1978). "Attitudes of caretakers toward the sexual behaviour of mentally retarded persons." American Journal of Mental Deficiency **83**(3): 289-296.

Moffat, S. (2001). Inferno. Coupling, Series One: Episode four. London, British Broadcasting Corporation.

Monat-Haller, R. K. (1992). Understanding and expressing sexuality: Responsible choices for individuals with developmental disabilities. Baltimore, Paul H. Brookes Publishing.

Moore, S. and D. Rosenthal (1993). Sexuality in adolescence. London, Routledge.

Morris, P. (1969). Put away: A sociological study of institutions for the mentally retarded. London, Routledge & Kegan Paul.

Mosier, H. D., H. J. Grossman, et al. (1962). "Secondary sex development in mentally deficient individuals." Child Development **33**(273-286): 273-285.

Mulhern, T. J. (1975). "Survey of reported sexual behaviour and policies characterising residential facilities for retarded citizens." American Journal of Mental Deficiency **79**(6): 670-673.

Murphy, G. H. (2000). "Justice denied." Mental Health Care **3**(8): 256 - 257.

Murphy, G. H. and I. C. H. Clare (1997). Consent issues. Adults with learning disabilities: A practical approach for health professionals. J. O'Hara and A. Sperlinger. Chichester, John Wiley & Sons: 171-185.

Murphy, G. H. and M. A. Feldman (2002). "Editorial: Parents with intellectual disabilities." Journal of Applied Research in Intellectual Disabilities **15**(4): 281-284.

Murphy, W. D., E. M. Coleman, et al. (1983). Human sexuality in the mentally retarded. Treatment issues and innovations in mental retardation. J. L. Matson and F. Andrasik. New York, Plenum Press: 581-643.

Murray, J. L., R. A. R. MacDonald, et al. (1999). "Staff attitudes towards the sexuality of individuals with learning disabilities: A service-related study of organisational policies." British Journal of Learning Disabilities **27**: 141-145.

Murray, J. L., R. A. R. MacDonald, et al. (1995). "Staff attitudes towards individuals with learning disabilities and AIDS: The role of attitudes towards client sexuality and the issue of mandatory testing for HIV infection." Mental Handicap Research **8**(4): 321-332.

Murray, J. L. and P. M. Minnes (1994). "Staff attitudes towards the sexuality of persons with intellectual disability." Australia and New Zealand Journal of Developmental Disabilities **19**(1): 45-52.

National Assembly for Wales (2000). In safe hands: Implementing Adult protection procedures in Wales. Cardiff, National Assembly for Wales and The Home Office.

National Assembly for Wales (2000a). A Strategic Framework For Promoting Sexual Health in Wales. Cardiff, Health Promotion Division, National Assembly of Wales.

National Assembly for Wales (2001). Fulfilling the promises: proposals for a framework for services for people with learning disabilities. Cardiff, Learning Disability Advisory Group, National Assembly for wales.

Nemeth, M. and B. Johnson (1995). "Nobody has the right to play God." Maclean's **108**(26): 17.

Nettleton, S. and J. Watson (1998). The body in everyday life: an introduction. The body in everyday life. S. Nettleton and J. Watson. London, Routledge: 1-24.

Neugebauer, R. (1996). Mental handicap in mediaeval and early modern England - criteria, measurement and care. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Newens, A. J. and R. McEwan (1995). "AIDS/HIV awareness training for young people with severe learning difficulties: an evaluation of two school programmes." Journal of Advanced Nursing **22**: 267-275.

Nightingale, C. (2000). "Barriers to health access: a study of cervical cancer screening for women with learning disabilities." Clinical Psychology Forum **137**: 26-30.

Nirje, B. (1973). The normalization principle - implications and comments. Advances in the care of the mentally handicapped. H. C. Gunzburg. Birmingham, British Society for the Study of Mental Subnormality.

Norrie, A. (1993). Crime, reason and history: A critical introduction to criminal law. London, Weidenfeld & Nicolson.

Nunkoosing, K. and M. John (1997). "Friendships, relationships and the management of rejection and loneliness by people with learning disabilities." Journal of learning Disabilities for Nursing, Health and Social Care **1**(1): 10-18.

Nursing and Midwifery Council (2002). Code of Professional Conduct. London, Nursing and Midwifery Council.

Nursing and Midwifery Council (2002a). Practitioner-client relationships and the prevention of abuse. London, Nursing and Midwifery Council.

Nye, R. A. (1999). Introduction - On why history is so important to an understanding of human sexuality. Sexuality. R. A. Nye. Oxford, Oxford University press: 3 - 15.

O'Brien, J. (1989). What's worth working for? Leadership for better quality human services. Lithonia, Georgia, Responsive Systems Associates.

O'Conner, C. R. and J. Rose (1997). "Sexual offending and abuse perpetrated by men with learning disabilities: An integration of current research concerning assessment and treatment." Journal of learning Disabilities for Nursing, Health and Social Care **2**(1): 31-38.

O'Connor, N. and J. Tizard (1956). The social problem of mental deficiency. London, Pergamon Press.

Ogden, J. (1992). Fat chance! The myth of dieting explained. London, Routledge.

O'Hara, J., B. Carmichael, et al. (1997). Personal perspectives on learning disabilities. Adults with learning disabilities: A practical approach for health professionals. J. O'Hara, & Sperlinger, A. Chichester, John Wiley & Sons: 31-43.

Oliver, B. E., G. B. Simon, et al. (1973). Group discusions with adolescent female patients in a mental subnormality hospital. Advances in the care of the mentally handicapped. H. C. Gunzburg. Birmingham, British Society for the Study of Mental Subnomality / Balliere Tindall: 150-154.

Oliver, M. (1990). The politics of disablement. Basingstoke, Hampshire, Macmillan.

Oliver, M. (1996). Understanding disability: From theory to practice. London, Macmillan.

Osborne, R. (1993). Freud for beginners. London & New York, Writers and Readers Publishing.

Ousley, O. Y. and G. B. Mesibov (1991). "Sexual attitudes and knowledge of high-functioning adolescents and adults with autism." Journal of Autism and Developmental Disorders **21**(4): 471-481.

Owen, S. (2001). "The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients." Journal of Advanced Nursing **36**(5): 652-658.

Padgug, R. (1999). Sexual matters: on conceptualising sexuality in history. Culture, Society and Sexuality. R. Parker and P. Aggleton. London, University College London Press: 15-28.

Pannell, J., K. Simons, et al. (2000). Paid work and housing, a comparative guide to the impact of employment on housing and support for people with learning disabilities. Brighton, Joseph Rowntree Foundation in conjunction with Pavilion Publishing.

Parker, R. and P. Aggleton (1999). Introduction. Culture, society and sexuality. R. Parker and P. Aggleton. London, UCL Press: 1 - 9.

Parker, T. and P. R. Abramson (1995). "The law hath not been dead: Protecting adults with mental retardation from sexual abuse and violation of their freedom." Mental Retardation 33(4): 257-263.

Parry-Jones, W. L. (1972). The trade in lunacy: a study of private madhouses in England in the eighteenth and nineteenth centuries. London, Routledge.

Pearsall, J., Ed. (2002). Concise Oxford English Disctionary. Oxford, Oxford University Press.

Pease, B. (2000). Recreating men: Postmodern masculinity politics. London, Sage.

Peel, R. A., Ed. (1998). Essays in the history of eugenics. London, The Galton Institute.

Perrin, B. and B. Nirje (1989). Setting the record straight: a critique of some frequent misconceptions of the normalisation principle. Making Connections: Reflecting on the lives and experiences of people with learning disabilities. A. Brechin and J. Walmsley. London, Hodder & Stoughton in association with the Open University.

Petersen, A. (1998). Unmasking the masculine: Men and identity in a sceptical age. London, Sage.

Peterson, A. and R. Bunton (2002). The new genetics and the public's health. London, Routledge.

Pittock, F. and M. Potts (1988). "Neighbourhood attitudes to people with a mental handicap: A comparative study." British Journal of Subnormality 34(1): 35-46.

Plummer, K. (1995). Life story research. Rethinking methods in psychology. J. A. Smith, R. Harre and L. v. Langenhove. London, Sage: 50-63.

Plummer, K. (2000). Mapping the sociological gay: Past, present and futures of a sociology of same sex relations. Lesbian and Gay Studies: An introductory, interdisciplinary approach. T. Sandfort, J. Schuyf, J. W. Duyvendak and J. Weeks. London, Sage: 46-60.

Polce-Lynch, M., B. J. Myers, et al. (2001). "Adolescent self-esteem and gender: Exploring relations to sexual harrassment, body image, media influence, and emotional expression." Journal of Youth and Adolescence 30(2): 225-244.

Potter, J. (1996). Discourse analysis and constructionist approaches: Theoretical background. Handbook of qualitative research methods for psychology and the social sciences. J. T. E. Richardson. Oxford, British Psychological Society / Blackwell Books: 125-140.

Prosser, H. and J. Bromley (1998). Interviewing people with intellectual disabilities. Clinical psychology and people with intellectual disabilities. E.

Emerson, C. Hatton, J. Bromley and A. Caine. Chichester, John Wiley & Sons: 99-113.

Pueschel, S. M. and P. S. Scola (1988). "Parents' perception of social and sexual functions in adolescents with Down's syndrome." Journal of Mental Deficiency Research **32**: 215-220.

Rafter, N. H. (1997). Creating born criminals. Chicago, University of Illinois Press.

Rapley, M. (1995). "Black swans: Conversation analysis of interviews with people with learning disabilities." Clinical Psychology Forum: 17-23.

RCN (2000). Sexuality and sexual health in nursing practice. London, Royal College of Nursing.

RCN (2001). Sexual health strategy, guidance for nursing staff. London, RCN: 28.

Rees, L. M., O. Spreen, et al. (1991). "Do attitudes to persons with handicaps really shift over time? Comparison between 1975 and 1988." Mental Retardation **29**(2): 81-86.

Reid, D. A. (1995). "Sexual activity in people with learning diabilities." British Journal of Learning Disabilities **23**: 56-58.

Rentoul, R., R. (1906). Race culture; or, race suicide? (a plea for the unborn). London, Walter Scott Publishing Co.

Ricciardelli, L. A. and M. P. McCabe (2001). "Self-esteem and negative affect as moderators of sociocultural influences on body dissatisfaction, strategies to decrease weight and strategies to increase muscles among adolescent boys and girls." Sex Roles **44**(3/4): 189-207.

Riddell, S., S. Baron, et al. (2001). "The significance of the 'learning society' for women and men with learning difficulties." Gender and Education **13**(1): 57-73.

Rimmerman, A., B. Hozmi, et al. (2000). "Contact and attitudes towards individuals with disabilities among students tutoring children with developmental disabilities." Journal of Intellectual and Developmental Disability **25**(1): 13-18.

Rioux, M. H. (1997). "Disability: The place of judgement in a world of fact." Journal of Intellectual Disability Research **41**(2): 102-111.

Rioux, M. H. (2001). The many interests in genetic knowledge: An international perspective on prenatal screening ad the use of genetic information in relation to people with learning difficulties. Considered Choices? The new genetics, prenatal testing and people with learning disabilities. L. Ward. Kidderminster, BILD: 91-107.

Robson, C. (1993). Real world research: A resource for social scientists and practitioner researchers. Oxford, Blackwell.

Rodgers, J. (1999). "Trying to get it right: Undertaking research involving people with learning difficulties." Disability and Society **14**(4): 421-433.

Rose, J. and S. Holmes (1991). "Changing staff attitudes to the sexuality of people with mental handicaps: An evaluative comparison of one and three day workshops." Mental Handicap Research 4(1): 67-69.

Rose, J. and C. Jones (1994). Working with parents. Practice Issues in sexuality and learning disabilities. A. Craft. London, Routledge: 23-49.

Rosen, M., G. R. Clark, et al. (1977). Psychosexual adjustment. Habilitation of the Handicapped. M. Rosen, G. R. Clark and M. S. Kivitz. Baltimore, University Park Press: 251-275.

Ross, E. and R. Rapp (1997). A research note from social history and anthropology. The gender sexuality reader: culture, history, political economy. R. N. Lancaster and M. di Leonardo. New York, Routledge: 153 - 168.

Rothman, D. J. (1971). The discovery of the asylum: Social order and disorder in the new republic. Boston, Little, Brown and Co.

Rothman, H. (2000). "Disseminating the principles of the Universal Decalaration on the Human Genome and Human Rights." New Genetics and Society 19(1): 89-104.

Roy, M. and A. Roy (1988). "Sterilisation for girls and women with mental handicaps: Some ethical and moral considerations." Mental Handicap 16: 97-100.

Royal Commission (1908). Report of the Royal Commission on the care and control of the feeble minded. London, HMSO.

Rubin, G. S. (1999). Thinking sex: Notes for a radical theory of the politics of sexuality. Culture, society and sexuality. R. Parker, & Aggleton, P. London, UCL Press: 143-178.

Rushton, P. (1996). Idiocy, the family and the community in early modern north-east England. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Rutter, M. (2000). The impact of illness on sexuality. Caring for sexuality in health and illness. D. Wells. Edinburgh, Churchill Livingstone: 207 - 220.

Sampson, E. E. (1989). The deconstruction of the self. Texts of Identity. J. Shotter and K. Gergen. London, Sage: 1-19.

Sandfort, T. and H. Galesloot (2000). Crossing borders: A debate on the perspectives of women's studies and gay and lesbian studies. Lesbian and Gay Studies: An introductory, interdisciplinary approach. T. Sandfort, J. Schuyf, J. W. Duyvendak and J. Weeks. London, Sage: 175-194.

Sands, D. J. and E. B. Kozleski (1994). "Quality of life differences between adults with and without disabilities." Education and Training in Mental Retardation and Developmental Disabilities 29: 90-101.

Saunders, E. J. (1979). "Staff members' attitudes toward the sexual behaviour of mentally retarded residents." American Journal of Mental Deficiency 84(2): 206-208.

Scheerenberger, R. C. (1983). A history of mental retardation. Baltimore, Paul H. Brookes.

Schwandt, T. A. (2001). Dictionary of qualitiative enquiry. London, Sage.

Scior, K. (2000). "Women with learning disabilities: Gendered subjects after all?" Clinical Psychology Forum(137): 6-10.

Scott, L. and L. Kerr-Edwards (1999). Talking together about growing up: a workbook for parents of children with learning disabilities. London, Family Planning Association.

Scotti, J. R., B. S. Slack, et al. (1996). "College student attitudes concerning the sexuality of persons with mental retardation: Development of the perceptions of sexuality scale." Sexuality and Disability **14**(4): 249-263.

Scotti, J. R., K. J. Ujcich, et al. (1996). "Evaluation of an HIV/AIDS education program for family-based foster care providers." Mental Retardation **34**(2): 75-82.

Scull, A. (1989). Social order / Mental disorder: Anglo-American psychiatry inhistorical perspective. Berkeley, Los Angeles, University of California Press.

Scull, A. (1993). The most solitary of afflictions; madness and Society in Britain, 1700-1900. New Haven, Yale University Press.

Searle, G. R. (1976). Eugenics and politics in Britain, 1900-1914. Leyden, Leyden Noordhoff.

Searle, G. R. (1998). Eugenics: The early years. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute.

Searle, J. (1995). The construction of social reality. London, Penguin.

Sebba, J. (1981). "Sexual development in mentally handicapped people: A critical look at staff attitudes." Apex **9**(1): 22-23.

Sedgwick, P. (1982). Psychopolitics. London, Pluto.

Seidler, V., J. (1987). Reason, desire, and male sexuality. The cultural construction of sexuality. P. Caplan. London, Routledge: 82 - 112.

Seidler, V. J. (1997). Man enough: Embodying masculinities. London, Sage.

Seltzer, M. M. and L. C. Litchfield (1984). Community reaction to community residences: A study of factors related to community response. Proceedings of the sixth congress of the International Association for the Scientific Study of Mental Deficiency: Perspectives and progress in mental retardation. J. M. Berg. Baltimore, University Park Press. **1: Social, psychological and educational aspects:** 393-399.

Senior, V., J. A. Smith, et al. (2002). "Making sense of risk: An interpretative phenomenological analysis of vulnerability to heart disease." Journal of Health Psychology 7(2): 157-168.

Servais, L., D. Jacques, et al. (2002). "Contraception of women with intellectual disability prevalence and determinants." Journal of Intellectual Disability Research **46**(2): 108-119.

Sexual Offences Review Team (2000). Setting the boundaries: reforming the law on sex offences Volume 1. London, Home Office Communication Directorate.

Shakespeare, T. (1999). "The sexual politics of disabled masculinity." Sexuality and Disability **17**(1): 53-64.

Shakespeare, T., Gillespie-Sells., et al. (1996). The sexual politics of disability: Untold desires. London, Cassell.

Shanley, E. (1986). Aspects of development. Mental handicap: A handbook of care. E. Shanley. Edinburgh, Churchill Livingstone: 110-126.

Shanly, A. and J. Rose (1993). "A consumer survey of adults with learning disabilities currently doing work experience: Their satisfaction with work and wishes for the future." Mental Handicap Research **6**(3): 250-259.

Shapiro, E. S. and C. A. Sheridan (1985). "Systematic assessment and training of sex education for a mentally retarded woman." Applied Research in Mental Retardation **6**: 307-317.

Sharkey, V. B. (1997). "Sexuality, sexual abuse. Omissions in admissions?" Journal of Advanced Nursing **25**: 1025-1032.

Sheerin, F. (1998). "Parents with learning disabilities: A review of the literature." Journal of Advanced Nursing **28**(1): 126-133.

Sheerin, F. and D. Sines (1999). "Marginalisation and its effects on the sexuality-related potentials of the learning-disabled person." Journal of Learning Disabilities for Nursing, Health and Social Care **3**(1): 39-49.

Shepherd, G. (1987). Rank, gender, and homosexuality: Mombassa as a key to understanding sexual options. The cultural construction of sexuality. P. Caplan. London, Routledge: 240 - 270.

Shepperdson, B. (1995). "The control of sexuality in young people with Down's syndrome." Child: Care, Health and Development **21**(5): 333-349.

Sigelman, C. K., E. C. Budd, et al. (1981). "Asking questions of retarded persons: A comparison of yes-no and either-or formats." Applied Research in Mental Retardation: 347-357.

Sigelman, C. K., E. C. Budd, et al. (1982). "Evaluating alternative techniques of questioning mentally retarded persons." American Journal of Mental Deficiency **86**(5): 511-518.

Silverman, D. (2000). Doing qualitative research: A practical handbook. London, Sage.

Simons, K., T. Booth, et al. (1989). "Speaking out: User studies and people with learning difficulties." Research, Policy and Planning **7**(1): 9-17.

Sinason, V. (1992). Mental handicap and the human condition: New approaches from the Tavistock. London, Free Association Books.

Skelton, M. and C. Greenland (1979). Social work and mental retardation. Tredgold's mental retardation. M. Craft. London, Bailliere Tindall: 233-247.

Slattery, J. and K. Johnson (2000). Family, marriage, friends and work. Women with intellectual disabilities: Finding a place in the world. R. Traustadottir, & Johnson, K. London, Jessica Kingsley: 90-105.

Smith, J. A. (1999). "Identity development during the transition to motherhood: An interpretative phenomenological analysis." Journal of Reproductive and Infant Psychology **17**(3): 281-299.

Smith, J. A. (2003a). Validity and qualitative psychology. Qualitative psychology: A practical guide to research methods. J. A. Smith. London, Sage: 232-235.

Smith, J. A. (2004). Re: [ipaanalysis] Participant validation. ipaanalysis@yahoogroups.com, Jonathan Smith.

Smith, J. A. (2004a). Re use of 3rd or 1st person. P. Wheeler. London, Personal Communication.

Smith, J. A., P. Flowers, et al. (1997). Interpretative phenomenological analysis and the psychology of health and illness. Material discourses of health and illness. L. Yardley. London, Routledge: 68-91.

Smith, J. A., M. Jarman, et al. (1999). Doing interpretative phenomenological analysis. Qualitative health psychology: theories and methods. M. Murray and K. Chamberlain. London, Sage: 218-240.

Smith, J. A. and M. Osborn (2003). Interpretative phenomenological analysis. Qualitative psychology: A practical guide to research methods. J. A. Smith. London, Sage: 51-80.

Smyly, S. R. and J. D. Elsworth (1997). "Interviewing clients: A project to explore client views about a change in service provision." British Journal of Learning Disabilities **25**: 64-67.

Sobsey, D. (1994). Violence and abuse in the lives of people with disabilities: The end of silent acceptance? Baltimore, Maryland, Paul H. Brookes.

Solway, R. A. (1998). From mainline to reform eugenics. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute: 52-111.

Stalker, K. and P. Harris (1998). "The exercise of choice by adults with intellectual disabilities: A literature review." Journal of Applied Research in Intellectual Disabilities **11**(1): 60-76.

Stearns, P. N. (1997). Fat history: Bodies and beauty in the modern west. New York, New York University Press.

Stein, A. and K. Plummer (1994). "'I can't even think straight': Queer theory and the missing sexual revolution in Sociology." Sociological Theory **12**: 178-87.

Strike, R. and D. McConnell (2002). "Look at me, listen to me, I have something important to say." Sexuality and Disability **20**(1): 53-63.

Sundrum, C. J. and P. F. Stavis (1994). "Sexuality and mental retardation: Unmet challenges." Mental Retardation **32**(4): 255-264.

Swain, J., B. Heyman, et al. (1998). "Public research, private concerns: Ethical issues in the use of open ended interviews with people who have learning difficulties." Disability and Society **13**(1): 21-36.

Swain, J. and C. Thirlaway (1996). "'Just when you think you got it all sorted...': Parental dilemmas in relation to the developing sexuality of young profoundly disabled people." British Journal of Learning Disabilities **24**(2): 58-64.

Sweyn-Harvey, R. (1984). "Care staff attitudes to the sexuality of mentally handicapped hospital residents." Mental Handicap **12**(1): 28-29.

Switzky, H. N., M. Dudzinski, et al. (1988). Historical foundations of out-of-home residential alternatives for mentally retarded persons. Integration of developmentally disabled individuals into the community. L. W. Heal, Haney, J. I., & Novak-Amado, A. R. Baltimore, Paul H. Brookes: 19-35.

Taylor, S. J. and R. Bogdan (1989). "On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance." Disability, Handicap & Society **4**(1): 21-36.

Tepper, M. S. (1999). "Letting go of restrictive notions of manhood: Male sexuality, disability and chronic illness." Sexuality and Disability **17**(1): 37-51.

Thomas, D. and H. Woods (2003). Working with people with learning disabilities: Theory and practice. London, Jessica Kingsley.

Thompson, D. (1994). "Sexual experience and sexual identity for men with learning disabilities who have sex with men." Changes **12**(4): 254-263.

Thompson, D., Ed. (1996). The concise Oxford dictionary. London, BCA by arrangement with Oxford University Press.

Thompson, D. and H. Brown (1998). Reponse-ability: Working with men with learning disabilities who have difficult or abusive sexual behaviours - a manual for staff and managers. Brighton, Pavilion Publishing.

Thompson, D., I. Clare, et al. (1997). "Not such an 'ordinary' relationship: The role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour." Disability and Society **12**(4): 573-592.

Thompson, S. A., M. Bryson, et al. (2001). "Prospects for identity formation for lesbian, gay, or bisexual persons with developmental disabilities." International Journal of Disability, Development and Education **48**(1): 53-65.

Thompson, T. and P. Mathias, Eds. (1998). Standards and learning disability. London, Bailliere Tindall.

Thomson, M. (1996). Family, community and state: The micro-politics of mental deficiency. From idiocy to mental deficiency. D. Wright, & Digby, A. London, Routledge.

Timmers, R. L., P. DuCharme, et al. (1981). "Sexual knowledge, attitudes and behaviours of developmentally disabled adults living in a normalized apartment setting." Sexuality and Disability 4(1): 27-39.

Timson, J. (1998). Human genetics. Essays in the history of eugenics. R. A. Peel. London, The Galton Institute.

Tomlinson, D. R. (1991). Utopia, community care and the retreat from the asylums. Milton Keynes, Open University Press.

Toomey, J. F. (1993). "Final report of the Bawnmore personal development programme: Staff attitudes and sexuality programme development in an Irish service for people with mental handicap." Research in Developmental Disabilities **14**: 129-144.

Tredgold, R. F. and K. Soddy (1970). Tredgold's mental retardation. London, Bailliere, Tindall & Cassell.

Trent, J. W. (1995). "Suffering Fools: Can a simple re-definition change attitudes toward mental retardation or does a fate worse than labelling still await those at the bottom of the bell curve?" The Sciences(July / August, 1995): 18-22.

Twigg, J. (2002). "The body in social policy: Mapping a territory." Journal of Social Policy **31**(3): 421-439.

Udall, E. T. and J. A. Corbett (1979). Non-hospital residential care for adults with mental retardation. Community Care for the mentally disabled. J. K. Wing, & Olsen, R. Oxford, Oxford university Press: 132-151.

United Nations General Assembly (1971). Declaration of general and special rights of the mentally handicapped, 26th Session, Resolution 2865, United Nations.

Valenti-Hein, D. and J. R. Dura (1996). Sexuality and sexual development. Manual of diagnosis and professional practice in mental retardation. J. W. Jacobson, & Mulick, J.A. Washington, D.C., American Psychological Association: 301-310.

Van Dyke, D. C., D. M. McBrien, et al. (1995). "Issues of sexuality in Down's syndrome." Down Syndrome Research and Practice 3(2): 65-69.

Vance, C. S. (1999). Anthropology rediscovers sexuality: A theoretical comment. Culture, society and sexuality. R. Parker, & Aggleton, P. London, UCL Press: 39 - 54.

Victor, J. S. (1980). Human sexuality: A social psychological approach. London, Prentice Hall International.

Walker, A. and C. Walker (1998). "Normalisation and 'normal' ageing: The social construction of dependency among older people with learning disabilities." Disability and Society **13**(1): 125-142.

Walmsley, J. (1991). "Adulthood and people with mental handicaps: Report of a research project." Mental Handicap Research **4**(2): 141-154.

Walmsley, J. (1991a). "'Talking to top people': Some issues relating to the citizenship of people with learning difficulties." Disability, Handicap & Society **6**(3): 219-231.

Walmsley, J. (2000). "Women and the Mental Deficiency Act of 1913: Citizenship, sexuality and regulation." British Journal of Learning Disabilities **28**: 65-70.

Walmsley, J., D. Atkinson, et al. (1999). Community care and mental deficiency 1913 to 1945. Outside the walls of the asylum. The history of care in the community, 1750-2000. P. Bartlett, & Wright, D. London, Athlone Press: 180 - 203.

Walmsley, J. and S. Rolph (2001). "The development of community care for people with learning difficulties 1913 to 1946." Critical Social policy **21**(1): 59-80.

Ward, L., Ed. (2001). Considered choices? The new genetics, prenatal testing and people with learning disabilities. Kidderminster, BILD Publications.

Watson, D. (1997). Causes and manifestations. Learning disabilities. B. Gates. Edinburgh, Churchill Livingstone: 21-38.

Watson, J. (1998). Running around like a lunatic: Colin's body and the case of male embodiment. The body in everyday life. S. Nettleton and J. Watson. London, Routledge: 163-179.

Watson, N. (2002). "Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability." Disability and Society **17**(5): 509-527.

Waxman, B. F. (1994). "Up against eugenics: Disabled women's challenge to receive reproductive health services." Sexuality and Disability **12**(2): 155-171.

Weeks, J. (1986). Sexuality. London, Routledge.

Weeks, J. (1987). Questions of identity. The cultural construction of sexuality. P. Caplan. London, Routledge: 31 - 51.

Weeks, J. (1989). Sex, politics and society: The regulation of sexuality since 1800. London, Longman.

Weeks, J. (1995). Invented moralities: sexual values in an age of uncertainty. Cambridge, Polity.

Weeks, J. (2000). The challenge of lesbian and gay studies. Lesbian and Gay Studies: An introductory, interdisciplinary approach. T. Sandfort, J. Schuyf, J. W. Duyvendak and J. Weeks. London, Sage: 1-13.

Welsh Office (1983). All Wales strategy for the development of services for mentally handicapped people. Cardiff, Welsh Office.

Welshman, J. (1999). Rhetoric and reality: Community care in England and Wales, 1948-74. Outside the walls of the asylum. The history of care in the community, 1750-2000. P. Bartlett, & Wright, D. London, Athlone Press: 204 - 226.

Wendell, S. (1996). The rejected body: Feminist philosophical reflections on disability. London, Routledge.

Wheeler, P. (2001). "Sexuality: Meaning and relevance to learning disability nurses." British Journal of Nursing **10**(14): 920-927.

Wheeler, P. (2002). "Men and women with learning disabilities and consent to sexual relationships: A review of the current law and proposed changes." British Psychological Society Division of Clinical Psychology Faculty for Learning Disabilities Newsletter(1): 4-7.

Wheeler, P. (2003). Consent and capacity in relation to men and women with a learning disability. BPS, DCP Faculty for learning disabilities annual conference: 'Focus on practice, theory, research and clinical skills, London, British Psychological Society.

Wheeler, P. (2003a). "Criminal law, sexuality and men and women with learning disabilities:Protection v empowerment." Tizard Learning Disability Review **8**(3): 21-29.

Wheeler, P. (2003b). "Patients' rights: Consent to treatment for men and women with a learning disability or who are otherwise mentally incapacitated." Learning Disability Practice **6**(5): 29-37.

Wheeler, P. (2004a). "Sex, the person with a learning disability and the legal framework." Learning Disability Practice **7**(3): 32-38.

Wheeler, P. and R. Jenkins (2004). "The management of challenging sexual behaviour." Learning Disability Practice **7**(5): 28-36.

Whitcraft, C. J. and J. P. Jones (1974). "A survey of attitudes about sterilisation of retardates." Mental Retardation **12**: 30-33.

White, E. and R. Barnitt (2000). "Empowered or discouraged? A study of people with learning disabilities and their experience of engaging in intimate relationships." British Journal of Occupational Therapy **63**(6).

White, I. (2002). Facilitating sexual expression: Challenges for contemporary practice. The challenge of sexuality in healthcare. H. Heath, & White, I. Oxford, Blackwell Sciences: 243-263.

Whitehead, S. M. (2002). Men and Masculinities: Key themes and new directions. Oxford, Polity Press.

Wilkins, G. (2002). Statistics re 'defectives'. personal communication to Wheeler. P.

Williams, L. and M. Nind (1999). "Insiders or outsiders: Normalisation and women with learning difficulties." Disability and Society **14**(5): 659-672.

Williams, M. (2003). Making sense of social research. London, Sage.

Wilson, A. R. (1995a). Introduction. A simple matter of justice:Theorizing Lesbian and Gay politics. A. R. Wilson. London, Cassell: 1-9.

Winchester, R. (2000a). "We are shocked." Community Care(1306, Jan 27): 17.

Winchester, R. (2000b). "Pressure builds to revamp consent laws in wake of failed rape charge." Community Care(3 February, No.1307): 10 -11.

Wing, J. K. (1979). Trends in the care of the chronically mentally disabled. Community Care for the mentally disabled. J. K. Wing, & Olsen, R. Oxford, Oxford university Press: 1-13.

Wing, L. and J. Gould (1979). Caring for the mentally retarded. Community care for the mentally disabled. J. K. Wing, & Olsen, R. Oxford, Oxford University Press: 106-131.

Wolf, L. and D. E. Zarfas (1982). "Parents' attitudes toward sterilization of theri mentally retarded children." American Journal of Mental Deficiency **87**(2): 122-129.

Wolfe, P. S. and W. J. Blanchett (2000). "The right to sexual expression: Moving beyond denial, suppression and fear to embracing the sexuality of people with disabilities." TASH Newsletter(May, 2000): 5-7.

Wolfensberger, W. (1972). The principles of normalisation in human services. Toronto, National Institute on Mental Retardation.

Wolfensberger, W. (1975). The origin and nature of our institutional models. Syracuse, N.Y, Human Policy Press.

Wolfensberger, W. (1995). "Social role valorization is too conservative. No, it is too radical." Disability and Society **10**(3): 365-367.

Wright, D. and A. Digby, Eds. (1996). From idiocy to mental deficiency. London, Routledge.