

The Sexual Lives and Identities of Women with Learning Disabilities:  
Exploring the Significance of Social Norms and Institutional Practices

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September 2007

## **Abstract**

This thesis explores how a small group of women with learning disabilities give meaning to sexuality, and how institutional processes within family and service settings influence this. It focuses on empirical data gained primarily from interviews with sixteen women, supplemented and contextualised by data drawn from a focus group with six women, and observations of a course on sexuality for men and women with learning disabilities.

The theoretical framework draws on the social model of disability, which suggests that disability is socially produced; Foucauldian concepts of regulation and normalisation; and symbolic interactionist notions of how sexuality is constructed through social interaction, alongside Foucault's notion of sexuality being 'produced' via normative discourses. The research is therefore embedded within a framework that explores how women with learning disabilities are subject to a number of very particular regulatory sexual accounts and discourses, including those that relate specifically to 'learning disability', as well as gendered normative accounts that can act to compete with those in relation to learning disability, or work with, and underscore them.

The study therefore explores where and how this group learnt about sexuality, teasing out some of the institutional accounts and discourses around sexuality, learning disability and gender that respondents reported coming into contact with; the kinds of institutional practices that influenced the agency of respondents, thus underlining or challenging the kinds of accounts and discourses of sexuality they reported encountering; and the various accounts and discourses of sexuality reflected in respondents' own opinions in relation to sexuality, gender and learning disability.

Findings suggest that respondents were subject to contradictory accounts, discourses and practices in relation to sexuality within institutional contexts, and that these both underscored norms related to the label of 'learning disability', as well as gendered and (hetero)sexual norms. Respondents themselves expressed a range of views in relation to sexuality. However, many accounts reflected the norms they reported encountering within family and service settings.

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## **Acknowledgments**

Many thanks go to:

my Ph.D. supervisors, Prof. Diane Richardson and Dr Janice McLaughlin; to my postgraduate colleagues; to Prof. Jane Wheelock and John Vail; to the research participants, and those who supported them to be involved in the study; and to my friends and family, particularly Allen Brace and Andrew Hindle. I could not have completed this without any of you.

Thanks also to the Economic and Social Research Council for providing funding for this Ph.D.

# CHAPTER ONE

## Introduction

The barriers to the sexual self expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed. (Shakespeare 2000a)

### Introduction

The aim of this thesis is to explore how a small group of women with learning disabilities give meaning to sexuality, and how family and formal institutional processes might influence this. It focuses on empirical data gained primarily from interviews with sixteen women, supplemented and contextualised by data drawn from a focus group with six women, and observations of a course for people<sup>1</sup> with learning disabilities that over half of the interview and focus group participants had attended. Interviewees and focus group participants attended a women's group that met monthly.

The study explores where and how this group learnt about sexuality, teasing out some of the accounts and discourses around sexuality, learning disability and gender that respondents<sup>2</sup> reported coming into contact with; the kinds of family and service practices that influenced the agency of respondents, thus underlining or challenging the kinds of accounts and discourses of sexuality they reported encountering; and the various accounts and discourses of sexuality reflected in respondents' own opinions on sexuality, gender and learning disability. Whilst sexuality, learning disability and gender are, as I will argue, complex in their construction and interaction with each other, I hope to draw out the ways in which the women in this study gave meaning to sexuality, and negotiated a sense of sexual self.

In this chapter, I will begin by describing my reasons for conducting this research. I will go on to outline the context within which this study is situated, including the historical and contemporary policy contexts. I will then highlight some of the most

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<sup>1</sup> When I use the term 'people' I refer to men and women with learning disabilities. I do not suggest by this that men's and women's experiences are the same, or that the use of the term 'people' is not problematic.

<sup>2</sup> My use of 'respondent(s)' refers to focus group participants *and* interviewees (but not those I observed during participant observation), unless stated otherwise.



pertinent literature in the topic area and attempt to situate my own research within it. In doing so I will argue that the subject of sexuality and learning disability has been under-researched, and the way in which people with learning disabilities give meaning to sexuality, particularly so. I will go on to discuss some of the key concepts used within the thesis. I will conclude by providing an outline of each of the chapters that will follow.

### **Focusing In On the Research Topic**

The decision to do this research has been greatly influenced by my own experiences of working with people who have learning disabilities in residential and day services<sup>3</sup>. Whilst these services were based on promoting the rights of people with learning disabilities, it was clear that their sexual rights<sup>4</sup> (as well as their rights more generally) were not always recognised or met. Further, education on sexuality for service users tended to occur only when service users showed an interest in sexuality (both male and female). Although training on sexuality was provided to staff in one institution in which I had worked, no policies existed in *any*, except on the occasion of a male and female service user in this same institution beginning to have what was assumed to be a sexual relationship.

My focus on gender stems in part from the way in which some of the women that I had worked with had their sexuality ‘policed’, for example, being encouraged to wear ‘appropriate’, non-revealing clothing, or to use particular types of contraception, like the pill. Although men too were sometimes policed, as a woman, I was interested in exploring this in specific relation to female service users.

When I began planning this research my focus was therefore on formal institutional processes within residential and (possibly) day service settings, and their impact on the sexuality of women who have learning disabilities. Early on in the research process my interest shifted to a more specific focus on how women with

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<sup>3</sup> I worked in three different organisations over a period of ten years, in both residential and day services, and within the public and voluntary sectors.

<sup>4</sup> When using the term ‘sexual rights’, I mean having the right to take part in sexual practices (or not), to have sexual relationships (or not) and the right to a sexual identity (Richardson 2000), as well as the right to imagine that these are possible (Cornell 1995, 1998).

learning disabilities felt in relation to sexuality: I realised that I did not want to focus on what this group did or did not do sexually, but more on their *feelings* on the subject: did they see themselves as sexual? Did others (particularly services and service staff) see them as sexual? What kinds of things (discourses and practices) impacted on this?

A later shift in focus occurred during fieldwork when respondents referred as often to family as to service influences. Thus my definition of ‘institutional’ widened to include family, as well as other institutions such as the media. At this point my original intentions of interviewing professionals (both in relation to gaining their opinions or accounts of their experiences, and as key informants) and conducting a full discourse analysis of policy documents (both national and organisational) were abandoned on this basis. However, policy documents have nevertheless been analysed and drawn upon to some extent, in order to explore and critique the institutional contexts within which services operate. In the final writing-up stage the focus narrowed again to include only family and formal institutions as these were the most frequently discussed during interviews. As I will highlight in Chapter Three, the resources available to me as a student researcher, including financial and social/cultural resources, dictated to some degree the way in which the research was finally conducted.

## Context

In this section I will look at the context relating to the sexuality and rights of people with learning disabilities. I will highlight some general historical and cultural discourses, move on to look at policy discourses, and conclude by describing some specific policies that reflect the move towards recognising disabled people’s rights<sup>5</sup>, including sexual rights. I will highlight however, how some of these policies remain problematic.

### *Historical and Cultural Discourses of Sexuality*

As I will describe more fully in Chapter Two, it has been argued that the concept of ‘disability’ emerged from medical discourses that developed in tandem with the

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<sup>5</sup> When I refer to ‘disabled people’, rather than people with learning disabilities, I mean disabled people generally. I discuss this wider group at times because of some of the commonalities that this group experience.

industrial revolution within Western capitalist countries like the UK (Finkelstein 1980, Oliver 1990). This involved an increase in medical and state intervention in the lives of disabled people, who were increasingly diagnosed, labelled, categorised and regulated. They were also cast as ‘other’ (Hevey 1992, Shakespeare 2000b): as Brigham (2000) describes, this was an era where boundaries were drawn between class, gender, the public and private, and normality and abnormality. Thus, such boundaries were associated with notions of pollution and degeneracy (Weeks 1989), that seemed to cross the particular boundaries *between* the different groups of those designated ‘other’ (Davis 1997).

People with learning disabilities became associated with criminality (Cox 1996, Jackson 1996a, Brigham 2000), and particular kinds of women with criminality, ‘idiocy’ and feeble-mindedness (Brigham 2000, Carey 2003). Discourses associated with working class women such as a dangerous sexuality that was associated with permissiveness and pollution, both physical and moral (Walkowitz 1980, Weeks 1989, Mason 1995), also became associated with women who had learning disabilities<sup>6</sup>, who were seen as both more sexually ‘dangerous’ (McDonagh 2000, Walmsley 2000) than men and other women by mainstream society. As McDonagh (2000:49) suggests, they were ‘reduced to the essential, yet disruptive element of feminine sexuality’ whilst those non-disabled women who ‘exhibited’ an ‘immoral sexuality’ were labelled ‘feeble-minded’ (Cox 1996, Thomson 1996, Brigham 2000). Thus, an ‘inappropriate’ sexuality, vulnerability, being ‘feeble-minded’ or of the lower classes, and female, seemed to fuse

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<sup>6</sup> Although the label ‘learning disability’ was not in use at this time, it is likely that many who are now ascribed this label would have been described as belonging to one or more of the categories that were targeted by eugenic policies (e.g. ‘feeble-minded’, ‘imbecile’, ‘defective’ or ‘idiot’). The 1913 Mental Deficiency Act classified ‘defectives’ (i.e. those who fell under the act) as ‘idiots’ (‘people who are so deeply defective in mind from birth or from an early age as to be unable to guard themselves against common physical dangers’); ‘imbeciles’ (‘persons who, whilst not as defective as idiots, were still incapable of “managing their own affairs”’); ‘feeble-minded persons’ (‘persons who were not as defective as imbeciles but required “care, supervision and control for their own protection and the protection of others”’); and ‘moral defectives’ ‘who “from an early age display some permanent mental defect coupled with strong vicious or criminal propensities on which punishment has had little or no effect”’ (Race 2002b:30).

together, underpinning the eugenic imagination<sup>7</sup> that became particularly prevalent in the early twentieth century.

Nevertheless, Brigham (2000) and Keywood (2001) highlight how women with learning disabilities were also seen at times, perhaps paradoxically, as *asexual*. Certainly, the sense that women with learning disabilities, were more ‘innocent’ in some ways than others is highlighted by the way in which, as Thomson (1996) describes, women with learning disabilities were seen as in need of protection from ‘moral vice’, as well as representing a form of sexual threat. Both Thomson (1996) and Brigham (2000) agree that the regulation of this group was based on supposedly moral grounds, although these moral grounds also melded with eugenic fears that this group would reproduce; as Digby (1996:11) suggests: ‘feeble-minded women in particular were seen as a source of a biological perpetuation of mental deficiency, and as a sexual threat to respectability and normal family life.’ Further, ‘feeble-minded’ people were seen to be ‘abnormally fertile’ (Walmsley 2000:66). Thus being ‘feeble-minded’ was directly linked to the ‘perpetuation’ of ‘mental deficiency’, to ‘dangerous’ and ‘threatening’ sexuality, to vulnerability, to moral degeneracy and to criminality. Such discourses helped to influence and legitimate the physical and social segregation and institutionalisation of this group of women. The medicalisation and categorisation of this group via social institutions such as family, education, work as well as social welfare, therefore made possible the regulation of this group in relation to eugenic concerns (Carey 2003).

A move from these highly regulatory discourses to rights-based discourses began to take hold in the mid twentieth century. Discourses of community care and normalisation began to be influential in this process (Digby 1996), as I will describe. Additionally, an increasing concern about the conditions in the long-stay hospitals in which many people with learning disabilities lived (Beadle-Brown *et al.* 2004, Digby 1996) also played its part. These changes also took place within a changing political climate where minority rights, including gender, ethnic and disability rights, were being fought for. Alongside this focus, it also seems that a focus on the vulnerability of people

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<sup>7</sup> ‘Eugenics’ was a term coined by Francis Galton in 1883. It describes the Darwinian-inspired belief in the need to improve ‘the physical and mental health of the nation’ which evolved in some European countries (including Britain) and the USA (see Borsay 2005:101-2).

with learning disabilities, both male and female, strengthened, a suggestion that I will return to later.

The discourses associated with the social model of disability, which will be discussed in more detail in the next chapter, have been particularly influential in both identifying and challenging medical discourses, as well as discourses of 'deviance', that have been perceived of as 'truths' in relation to disability. The social model defines disability as a category, a social construction which is in part created by the exclusion of disabled people from the mainstream<sup>8</sup>. The model analytically separates disability from the notion of impairment (the physical or intellectual restriction of the individual) (Oliver 1990) and is entangled with the growth of the disability movement, which gathered momentum in the 1960s (Campbell and Oliver 1996). In challenging the notion of disability as an innate and individual 'problem', the social model has highlighted the way in which disabled people are *constructed* as sexually dangerous or asexual (Tepper 2000).

### *Policy Discourses and Frameworks*

Policy discourses in particular have changed over time. Eugenic discourses were, to some extent, influential in relation to policy and so, for a time, policy discourses reflected wider discourses that framed women with learning disabilities as dangerous as well as vulnerable. For example, Borsay (2005:102) describes how the Eugenics Education Society, founded in 1907, advocated sterilisation, marital regulation, birth control and segregation to prevent the 'degeneration' of the populace. These eugenic concerns were expressed in policies such as the 1913 Mental Deficiency Act that set out plans to identify 'defectives' and detain them in local authority institutions (Painz 1993, Cox 1996, Jackson 1996a, Thomson 1996, Fido and Potts 1997, Borsay 2005). Whilst men and women were covered by the act, Walmsley (2000:69) has argued that men tended to be targeted for 'unruly or unlawful behaviour', whereas women were targeted for their inappropriate *sexual* behaviour. Sterilisation was also common (Painz 1993)

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<sup>8</sup> By 'mainstream' I refer to a 'non-disabled' wider society, on the basis that disabled people are sometimes socially and/or physically segregated from that.

although as Kerr and Shakespeare (2002) suggest, compulsory sterilisation was never fully endorsed in the UK. Thus, policy reflected and reinforced wider cultural beliefs about the nature of learning disability (Borsay 2005).

Whilst such discourses reflected the need to regulate the sexuality of women with learning disabilities, rights-based discourses began to emerge in the mid-twentieth century, as suggested. These were bound up with deinstitutionalisation and community care discourses, as well as what is called normalisation. Here I will focus on normalisation, and an associated concept, social role valorisation (SRV), which have particularly influenced the way in which learning disability services have been provided in the UK (Race 2002a). Flynn, writing in 1989, states that 'Rarely is a job advertised in this field (learning disability services) without some reference to the philosophy [of normalisation]' (1989:6) and that normalisation has been acknowledged to have 'laid the groundwork for the implementation and evaluation of deinstitutionalisation efforts'<sup>9</sup> (1989:6).

Normalisation was first developed in Scandinavia in the late 1960s by Bengt Nirje (1980) and Neils Bank-Mikkelsen (1980). Nirje (1980:33) describes normalisation, expressed through services, as 'making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society.' Bank-Mikkelsen (1980:56) also states that normalisation involves 'bringing them (people with learning disabilities) the legal and human rights of all other citizens.' Although normalisation did not initially call for non-segregated services, normalisation did call for service change.

In Canada, Wolf Wolfensberger adopted and transformed normalisation within the North American context, and described it as the 'utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviour and characteristics which are as culturally normative as possible' (1972:28). Wolfensberger (1983) later developed his version of normalisation into what he called social role valorisation (SRV), which could be applied to any 'devalued' person, and

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<sup>9</sup> Deinstitutionalisation refers to the policy move towards providing services for people with learning disabilities in the community rather than in large-scale hospital institutions.

referred to his belief that to be accepted by wider society, devalued people needed to adopt socially valued roles. Although Wolfensberger felt that society was at fault – that it was wrong to devalue people – his model focuses on changing people with learning disabilities to avoid this devaluation rather than attempting to change the way society ‘creates’ devalued categories. Wolfensberger’s formulation therefore represents a move from the Scandinavian emphasis on changing services and on gaining collective rights, to a focus on changing individuals and on individual rights (Schroeder and Schroeder 1981).

In the British context, John O’Brien’s restated version of normalisation (rather than SRV), which was developed in the USA, was particularly influential. He described this as ‘the use of means which are valued in our society in order to develop and support personal behaviour, experiences and characteristics which are likewise valued’ (1981:1). This formulation appears to bring together influences from the Scandinavian strand of normalisation, as well as the Canadian. For example, he describes service achievements in terms of ‘the personal appearance of people (and) the public image of people’ (1981:2), clearly reflecting Wolfensberger’s emphasis on image, and the social role. At the same time, he appears to support a rights-based and service-orientated Scandinavian model, which is apparent in his emphasis on the role that services should play in meeting the needs of people with learning disabilities. This amalgamation is apparent in what O’Brien (1989) called his ‘five service accomplishments.’ These accomplishments focus on supporting service users in community participation, on helping service users to contribute (in relation to work and social life), to promote service users’ choice, to encourage service users develop socially-valued roles, and to develop a community presence.

Although Scandinavian and North American versions of normalisation have influenced policy provision in the UK, Williams and Nind (1999) argue that O’Brien’s model has been the most influential, and Williams (2002:64) suggests that ‘Most services express allegiance to what has become known as the “the five service accomplishments” delineated by O’Brien.’ Many service organisations run courses in normalisation and reflect, though do not necessarily explicitly refer to, O’Brien’s service ‘accomplishments’ in their policies. Government policies, for example the *Valuing*

*People* White Paper (Department of Health 2001a), also reflect the values of normalisation in its aims to ensure that service users are accorded rights, choice, inclusion and independence (although *Valuing People* does not refer to normalisation, SRV, or O'Brien's service accomplishments explicitly). It might also be argued that the *Valuing People* White Paper also appears to reflect a social model (described later), particularly with its focus on rights, and its acknowledgement that some people with learning disabilities are 'pushed to the margins of our society' (Department of Health 2001a:1).

Despite this apparent 'take-up' of O'Brien's interpretation of normalisation in the UK, Wainright (1999) has highlighted that neither normalisation nor social role valorisation are significantly influential in the service policies of voluntary organisations, and further suggests that wider UK policy is more greatly influenced by it than local policy. As Deeley (2002) has suggested, normalisation has not been adhered to consistently within services. These differences in viewpoint might be influenced by the way in which, as Flynn and Nitsch (1980:xi) suggest, that 'all manner of ideas and practices are lumped together under the rubric of "normalization".' This appears to have led to a number of different interpretations (Brechin and Swain 1989, Painz 1993) and misinterpretations of the concept in practice; 'in some cases it has been misinterpreted so perversely as to produce implications and programmes directly opposite to the principle' (Perrin and Nirje 1989:220). Wolfensberger (1999) himself has described this use of normalisation as an oversimplification of the concept. In the following chapter I will critique normalisation and SRV further, particularly in terms of the way in which they might act to coerce people with learning disabilities into particular sexual and gendered normative roles.

What is called person-centred planning (PCP) has also become increasingly influential within services, and is explicit and central to the ethos of the *Valuing People* White Paper (Department of Health 2001a). John O'Brien was involved in PCP's development, which began in the mid-1980s, and it is embedded within the principle of normalisation as specifically applied by Wolfensberger (O'Brien *et al.* 1997). Person-centred planning, as the name suggests, figuratively places the individual at the centre of service provision, rather than fitting the individual into an existing framework of



services. In a sense mirroring the medical/social model distinction discussed both in this chapter and the next, O'Brien *et al.* (1997:481) state that PCP represents a move from services asking questions such as 'What's wrong with you and how can professionals fix it?' to 'What works well for you and what does not?' It also seeks to take a creative approach to not only meeting people's needs, but to help them achieve their wider goals and aspirations (O'Brien *et al.* 1997). Family and friends are viewed as central to the process of PCP, both in terms of identifying needs/goals/aspirations and in meeting them; community too is seen in terms of potential support (Beadle-Brown 2005).

O'Brien *et al.* (1997:480), however, acknowledge that 'an idea's utility lasts only as long as people apply it mindfully.' As such, like other service initiatives (for example normalisation), PCP has the potential to be applied inconsistently (Beadle-Brown 2005). In confirmation of this theory, Burton and Kagan (2006) point out that the first major study into PCP's effectiveness shows mixed outcomes, suggesting unevenness in its implementation. Many (for example, Brown and Scott 2005, Mansell and Beadle-Brown 2005 and Burton and Kagan 2006) argue that adequate funding and staff training are key to both PCP's success, and meeting people's needs more generally, and that this might be lacking.

Others take issue with the concept itself. Burton and Kagan, for example, argue that Valuing People's 'key messages', including its emphasis on PCP, are 'voluntaristic, individualistic and romantic' (2006:306). Focusing on PCP's relationship with these voluntaristic and individualistic aspects, Brown and Scott (2005) argue that PCP's needs-led focus on the individual threatens to deflect services from ensuring that pre-existing support networks are in place, particularly in relation to supporting those who have been abused. They also argue that PCP proponents tend to see such abuse as rare. However, it might also be argued that if PCP is needs-led, and that if abuse is not rare, services would, nevertheless (pre-existing or not), meet the needs of abused individuals, in theory at least. In relation to the 'romantic' nature of PCP, and its aim to meet the aspirations as well as needs of service-users, Mansell and Beadle-Brown note that PCP is 'extremely ambitious' (2005:21). They argue further that a focus on family and community as central to PCP processes ignores the social isolation that many people with learning disabilities experience. In addition, my own research, as I will discuss in

Chapter Five, suggests that families might make decisions that go *against* the stated desires of respondents with learning disabilities, and that family members might disagree between themselves over such decisions. Thus PCP might be seen as overly-idealistic since it is dependent on resources, as well as adequate and supportive social networks.

### *Policies: The Move from Eugenics to Sexual Rights*

In this section I will focus on specific policies impacting on the lives of people with learning disabilities. As suggested, eugenics, whilst mainly operating as and through particular discourses, did lead to formal policies, notably the 1913 Mental Deficiency Act. This Act contributed to the institutionalisation, physical/social segregation and regulation of large numbers of people with learning disabilities, and the segregation of women from men in such institutions (Fido and Potts 1997).

As suggested, a move from overt regulation to a discourse of rights has been influential within policy. The disability rights movement in particular has pushed the Government to introduce anti-discrimination policy in relation to disabled people, most notably achieved through the introduction of the Disability Discrimination Act (1995), which covers employment; trade organisations; goods, facilities, services and premises; education; and transport (Casserley 2000)<sup>10</sup> and the subsequent Disability Rights Commission (that began work in 2000). The disability movement has also been influential in the development of the notion of independent living for disabled people. Independent living in practice is a system whereby schemes are controlled by disabled people, offering them the knowledge and resources to help them live in their own homes (Oliver and Barnes 1998, Hasler 2004). The Government has taken this notion, and despite initial difficulties over funding such schemes (for example the Independent Living Fund), and the problematic involvement of third parties such as social workers and local authorities, the Community Care (Direct Payments) Act 1996, which became

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<sup>10</sup> It is worth noting however, that along with others, Borsay has described the Disability Discrimination Act as 'fundamentally flawed' (2005:1). For example Casserley (2000) highlights the way in which it is difficult to prove that discrimination has taken place, and argues that it legitimates discrimination (a view expressed by a number of people working within disability studies including Oliver and Barnes, 1998 and Drake, 1999).

law in 1997, allowed local authorities to make direct payments to disabled people to organise their own care (Oliver and Barnes 1998).

Deinstitutionalisation and 'community care' have also been bound up with the move towards rights discourses within policy settings. The 1971 White Paper *Better Services for the Mentally Handicapped* (Department of Health 2001a) initially mapped out the move to provide services within the community and the closure of long-stay hospitals. It sought to help people with learning disabilities live 'as normal a life as possible' (Department of Health 2001a:17). This reflected the wider move, beginning in the late 1950s, towards what was described as 'community care' (Morris 1993a). However, this wider discourse of 'community care' is not the only influence on the NHS and Community Care Act (1990) which seems to formalise it, and as Rolph *et al.* (2005:25) have suggested, 'Care in the community was not defined consistently, but meant different things at different times.' Thus, the Community Care Act also introduced commercial principles into the provision of care (Borsay 2005). As Glennerster (2000:190) argues, 'The community care reforms had little to do with care as such and a lot to do with saving public expenditure'. Holden (2004) emphasises the acceleration of this 'quasi market' since 1996 with mergers and acquisitions between major providers. One result of this has been the criticism that such marketisation has failed to bring more choice to those in receipt (or those apparently 'consuming') services, since the effects of the quasi-market has been to reduce choice to a narrow range of services and service-providers (Borsay 2005).

In 2001 the influential *Valuing People* White Paper (Department of Health 2001a) was introduced. This focuses specifically on people with learning disabilities. It describes 'four key principles': rights, independency, choice and inclusion, and explicitly recognises that these principles may not previously have been significant aspects of the lives of people with learning disabilities. Significantly the paper refers explicitly to the sexual rights of people with learning disabilities. It highlights the lack of social opportunities that this group have, and the accessible version of the *Valuing People* White Paper (Department of Health 2001b) states:

Lots of people with learning disabilities have few friends and are lonely. Help will be available to join in your local community and make friends. This might

be in paid or voluntary work, joining local clubs, taking part in local activities, having a relationship with friends or a partner, marrying, voting, having a flat or home, and living with the people you choose. People with learning disabilities have the same rights to all these things as everyone else and may need extra support with sex education and contraception.

Additionally, the *Valuing People* White Paper (Department of Health 2001a:81) states that ‘people with learning disabilities can be good parents and provide their children with a good start in life, but require considerable help to do so.’ This statement underlines the way in which policies have changed. Whilst there is some concern over the capability of people with learning disabilities to parent on their own, the document does not question the right of people with learning disabilities to parent. However, a significant omission within the document, reflected elsewhere within policy, is its lack of focus on gender and its potential impact on the experiences and rights of people with learning disabilities.

To complement the introduction of the White Paper, a Learning Disability Task Force was set up to advise the Government on implementation of the plan, and Learning Disability Partnership Boards were set up to ‘lead responsibility for ensuring implementation (Department of Health 2001a:9). One drawback is that these boards have no legal power to enforce change. Further, despite the presence of people with learning disabilities on such boards, professionals dominate (Fyson and Ward 2004). Fyson and Ward (2004:6) have also suggested that as a national policy, *Valuing People* might be of more ‘totemic than practical value’ as it is at local rather than national level that services are provided: the document is perhaps too far distanced from its practical application in organisational settings. Burton and Kagan have described *Valuing People* as ‘an uneasy amalgam of the progressive and the neoliberal, the romantic and the practical’ (2006:299), thus it reflects the economic principles that now underpin services (they operate within a quasi-market), whilst at the same time it sets up a possibly unachievable ideal (the quasi-market reduces choice, which impacts on rights, independence and inclusion).

Other potentially influential moves have included the introduction of the Learning Disability Awards Framework (LDAF) which was also introduced in 2001, and offers a formal qualification framework for those working in services, and covers

‘sexual expression’ and relationships<sup>11</sup>. Further, the Care Standards Act (2000)<sup>12</sup> introduced changes to registration and inspection and a new regulatory framework to ‘raise standards for people with learning disabilities who use services’, although this does not cover specifics such as relationships and sexuality. Additionally, the Code of Practice for Social Care Workers (2002), whilst not necessarily referring to sexuality, states that social care workers must *protect and promote* the rights of service users.

In relation to legislation and sexuality, Evans and Rodgers (2000) suggest that the law has taken a protectionist view in relation to people with learning disabilities, and this has been to the detriment of their individual sexual freedom. The recent Sexual Offences Act (2003), whilst representing as a significant shift in offering people with learning disabilities more protection from the law than they have previously had, particularly within service settings, has also been criticised. These criticisms centre on the increased range of people with learning disabilities covered by the Act, and because of its contested notion of ‘capacity’, as I will briefly discuss.

The ‘need’ to protect people with learning disabilities, is reflected widely within policy. Disabled people more generally are labelled alongside some other groups (like the elderly) as ‘vulnerable adults’, as seen in The Care Standards Act (2000) (Hasler 2004, Mandelstram 2005) and *No Secrets* (2000)<sup>13</sup> contains Government guidance on how agencies can protect ‘vulnerable people’, including adults with learning disabilities, from abuse.

These discourses of vulnerability, risk and protection sit uneasily alongside the rights discourses underpinning learning disability policy. The Code of Practice for Social Care Workers (General Social Care Council 2002), for example, states that whilst it expects those working in social care settings to promote independence and service user rights, including supporting service users to take risks, it also suggests *at the same time* that they must protect service users from ‘harm’ (section 4.2). The *Valuing People* White Paper emphasises that: ‘people with learning disabilities are amongst the most vulnerable and socially excluded in our society’ (Department of Health 2001a:1), but

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<sup>11</sup> See <http://www.ldaf.org.uk>.

<sup>12</sup> See <http://www.opsi.gov.uk/acts/acts2000/20000014.htm>.

<sup>13</sup> See [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@en/documents/digitalasset/dh\\_4074544.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@en/documents/digitalasset/dh_4074544.pdf).

also, like other documents, suggests that ‘support and protection... needs to be provided in a way which respects their own choices and decisions’ (Department of Health 2001a:93).

In relation to the Sex Offences Act (2003) specifically, one of the changes the Act has made to the law, is to move away from drawing a line between people labelled as having ‘severe’ learning disabilities (or labelled ‘defective’) and those as having ‘mild’ or ‘moderate’ learning disabilities (Robbins 1990, Gunn 1991). Those with ‘severe’ learning disabilities had previously been protected by law, whilst those with ‘mild’ or ‘moderate’ learning disabilities were assumed to be able to consent to sexual activity. The 2003 Act has taken on the notion of ‘capacity’ to consent. Whilst this usefully takes away the relatively rigid framework that only protected particular individuals labelled in particular ways, and provides protection to those who had not had such protection previously, it also increases the ‘reach’ of the law, both to protect, but also to intervene.

Further, Keywood (2003:31) suggests that the notion of ‘capacity’ obscures the way in which it is a construction, and an assessment of capacity ‘an instrument of power.’ Wheeler (2004) has also highlighted the difficulties in defining ‘consent’. Writing at the point at which the Sexual Offences Bill was put before Parliament, Keywood (2003) highlights, like Wheeler (2004) the tension between its position to both protect and empower, further suggesting that ‘services have typically sought to prioritise protection over empowerment.’ Keywood argues that this emphasis might, in part, be explained by the strength of the language and imagery associated with ‘victimisation and harm’ in relation to people with learning disabilities. Osgood (2005) has also suggested that this prioritisation might be explained by the way in which organisations seek to protect *themselves* from liability when managing risk, thus ‘playing it safe’ at the expense of the right of people with learning disabilities to negotiate risk as a necessary part of life. Wheeler (2004) has argued that the additional protection that the Sexual Offences Act provides within service settings might act to dissuade service staff from supporting people with learning disabilities to be sexual, since they face penalties should this be perceived in terms of sexual abuse.

Despite these viewpoints, Alaszewski and Alaszewski (2005) have argued that risk is less explicit within policy than it once was. They argue that, despite the potential for a focus on risk to impact on rights, risk *does* need to be explicitly addressed. Brown and Scott (2005) have also suggested that people with learning disabilities are not necessarily protected *enough* given their increased vulnerability to sexual abuse within institutional settings (Sobsey 1994).

Whilst it is likely that some people with learning disabilities are vulnerable due to their cognitive impairment, I would firstly argue that institutional arrangements and practices, as Sobsey (1994) suggests, are also influential in the construction of this vulnerability: for example, people with learning disabilities are put at risk of sexual abuse simply by living in institutional environments. Secondly, discourses of vulnerability, risk and protection might act as a form of constraint, as suggested, but further that such discourses might not always stem from a concern about the vulnerability of people with learning disabilities, but from within an institutional atmosphere of control. (Whilst Walmsley, 2005, in Traustadóttir and Johnson's edited collection of works that explore the experiences of women with learning disabilities, highlights the way in such control might be linked to apparent concerns around vulnerability in relation to long-stay institutions, Traustadóttir and Johnson have suggested that this link might also be made in relation to services provided in the community.) Whilst services are undeniably responsible for the welfare of those they provide services for, as Hasler (2004) argues, attention to risk, and subsequent health and safety measures, can reinforce the tendency of professionals to control and limit disabled people. Evans and Rodgers (2000:244) have even gone so far as to suggest that 'perhaps...the law is seeking not to protect the vulnerable, but rather to protect society from the vision of disabled people having a sexual persona.' As I will highlight in Chapter Two, the labelling of particular groups also makes possible their greater regulation by others. Thus, whilst I would not argue against the need to protect people with learning disabilities, I suggest that this protection can turn into a form of control.

To conclude this section then, it is clear that there have been significant changes in the cultural discourses, policy discourses and policy and legislative frameworks associated with people with learning disabilities and sexuality. However, there have also

been some continuities, particularly in the way in which people with learning disabilities are perceived to be at risk sexually.

One aspect of this research is to explore the accounts that institutions (in particular, family and services) give of sexuality, and its relationship with learning disability and gender. These accounts are contextualised by the ideological and practice-based changes associated with learning disability and sexual rights. In my data analysis chapters I explore the current context via the accounts of respondents, hoping to begin to map out how accounts of sexuality within institutional settings might reflect (or not) wider changes. In the next chapter I will also return to a number of critiques in relation to these.

## **Literature Review**

A particularly salient reason for doing this research is the dearth of literature on disability/learning disability and sexuality, or disability/learning disability/sexuality in relation to gender. Feminist researchers and theorists have been criticised for ignoring disabled women in their work (Morris 1991, Begum 1992), as well as women with learning disabilities (Traustadóttir and Johnson 2000), and disability researchers and theorists have been criticised for ignoring gender (McCarthy 1999). Furthermore, learning disability has often been ignored by academics working in the field of disability, or it has been assumed that people with learning disabilities face the same issues as other disabled people (McCarthy 1999, Goodley 2001). Here, I will outline the literature relating to disability and learning disability in relation to sexuality and gender, focusing primarily on empirical studies.

### *Sexuality and Learning Disability*

As suggested, relatively little research has been conducted about people who have learning disabilities in relation to sexuality, let alone more specific research in relation to *women* with learning disabilities and sexuality. Why such research has not been conducted is unclear. I would suggest three possible reasons for this: the historical view of sexuality and learning disability, and its apparent denial, as outlined previously, lack



of interest (people with learning disabilities, or their concerns, have not been seen as significant to researchers), and the way in which sexuality is still perceived to be a 'private' issue (Richardson 1996, 2000, Jackson 1999). Shakespeare (2000a) has highlighted this latter view in relation to disability-related research, suggesting that 'the private lives of disabled women and men were not seen as being equally worthy of concern' as issues of physical access and discrimination. This, he suggests, is perhaps due to the way in which the disabled movement drew inspiration from socialist and trade unionist styles of collectivism: the 'macho politics of disabled direct action.'

Significant research on the sexuality of people with learning disabilities, most of it small-scale, appears to have only been conducted in the last thirty years. This body of work coincides with the way in which normalisation, and its focus on rights, was beginning to take hold as a concept in both service settings and academia. This is reflected in a number of these studies. Early theoretical work is most significantly represented in the UK based work of Anne and Michael Craft (e.g. Craft and Craft 1978, Craft and Craft 1979, Craft 1980, Craft 1983, Craft 1987, Craft and Brown 1994). The Crafts underlined a rights-based approach to the provision of services, and the need to provide sex education for people with learning disabilities in relation to this. They highlighted a number of important themes in relation to sexuality and learning disability. These include the notion that sexuality is influenced by environment, that parents can fear sex and sex education, preferring to see people with learning disabilities as 'eternal children', that staff working in residential homes are under pressure to maintain the respectability of these homes, and that staff therefore see sex as negative – a problem to be solved, whilst also seeing residents' sexual behaviour as 'their' business. These factors, they argue, result in an atmosphere of overprotection and control where residents are unable to take sexual risks.

The Crafts thus highlighted the importance of social interaction in the development of sexuality, and the fear with which parents and professionals viewed the sexuality of people with learning disabilities, constructing them as childlike, and in need of protection and policing. They also highlighted the way in which sex can be constructed negatively, not only in terms of the 'risk' of sex and sexuality to people who have learning disabilities, but also in terms of service 'reputation' – service users'

expressions of sexuality have the potential to threaten the respectability of services themselves.

Whilst these are important insights, the Crafts' work is characterised by its reinforcement of 'traditional' or normative forms of sexuality – heterosexuality (Williams and Nind 1999) and marriage, and of a 'socially acceptable' sexuality (Craft 1983). These place values on different kinds of sexuality, devaluing those that are not considered the 'norm'. This restricts the choices that people with learning disabilities can make, and undermines the concept of rights on which normalisation is based. However, whilst Craft (1987) does not appear to see these norms as *necessarily* gendered, she does allude to the way in which men and women's experience might differ, highlighting, for example, that women have been seen at times as more 'dangerous' sexually than men.

In the Crafts' 1983 edited book *Sex education and counselling for mentally handicapped people*, a small number of studies relating to learning disability and sexuality were described. These studies reinforced some of the issues highlighted within the Crafts' own work, as well as identified some additional ones. The work of Brown (1983), for example, explores the sexual experiences of fifty young people with learning disabilities in a two-year residential programme in the UK. This showed that they were 'largely isolated from sexual information' (1983:132), with only one quarter receiving sex education. Many felt that they could not talk to their parents, and there was a 'say nothing and hope for the best' attitude which left the young people 'bewildered and vulnerable' (1983:132). Brown notes that the students had limited opportunities for exploration and in addition did not seem to 'own' their bodies – their bowel movements were documented and discussed 'over their heads', they were touched in a professional and impersonal way by carers, and that they had no real experience of privacy and consent. Brown expresses concern that in Adult Training Centres, sex education only occurred when 'unacceptable' behaviour was exhibited, and that sexual incidents were only dealt with on an individual *ad hoc* basis.

Again, these are important insights into the sexual world of people who have learning disabilities. Lack of information on sexuality, respondents' inability to talk to parents about sex, and the 'say nothing' culture suggest a 'silence' on sexuality which,

as I will argue later, is ‘productive’: sexuality is constructed as problematic. As Brown highlights, this leaves people with learning disabilities vulnerable, particularly so given that they are *already* constructed as such. The way in which privacy was virtually non-existent in this context and that sex education was only available when sexual behaviour was deemed ‘unacceptable’<sup>14</sup>, suggests a lack of consideration that service users would have sexual lives.

Koegel and Whittemore’s (1983) US study also focused on the experiences of men and women with mild learning disabilities, conducting a longitudinal study of 48 individuals over two and a half years. The importance of their study is in its emphasis on the diversity in attitude and experience between respondents, suggesting that people with learning disabilities cannot be treated as a homogeneous group. The research also suggested that respondents themselves changed over time, and thus their needs and problems also changed. One drawback of this study however, was its focus on people with mild impairments, who, it might be argued, would find it easier to enter sexual relationships, and to talk about them.

Much of the subsequent literature falls into three groups. The first group I describe explore staff and parent attitudes and practices in relation to the sexuality of people with learning disabilities. The second looks at this, *and* the experiences of people with learning disabilities themselves. The third focus specifically on the latter. Taking the first group, Robbins (1990) looks at sexuality in relation to the concept of ‘an ordinary life’. Robbins draws on the literature on sexuality available in 1990, interviews with social services staff from one local authority in the UK, and questionnaires with relatives and carers (numbers of participants were not given, although the range of the study appears to be large). Robbins highlighted similar issues to the Crafts, including the tendency of parents to be protective of their adult children, the way in which service staff tend to be mixed in their approach (some promote rights, others take a more protective parent-like approach and tend to be cautious), and the way in which the law seeks to protect. Robbins argues for better training and support for parents/staff, and policies based on promoting rights rather than minimising risk. Importantly, he suggests that sexuality is not necessarily ‘off-limits’, but that it is ‘managed’ and ‘policed’. Like

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<sup>14</sup> Although Brown does not describe what ‘unacceptable’ is, she links it with privacy and consent.

the Crafts, Robbins fails to question the concept of an 'ordinary life' and gender was not focused on. Additionally, he draws on both empirical data and others' research, but fails to make it clear when he is describing empirical findings or his own opinion. However, Robbins usefully highlights themes that are present in earlier research, suggesting that policy change was not at that time influencing practice to any great extent.

Swain and Thirlaway's (1996) UK study explored parental attitudes towards the sexuality of their 'profoundly disabled' children. Seven parents (five women, two men) were interviewed. An analysis of these interviews was presented at two workshops with thirty participants at each session, where a group discussion took place and a short questionnaire completed. This study is particularly interesting since it focused on *profoundly* disabled young people, and showed how complex the issue of sexuality is in relation to this group. For instance, touch was discussed as something that might rest at the borderline of abuse – can touch be, or when does touch become, abuse? Swain and Thirlaway argue that the notion of sexual rights formed no basis of the parents' thinking, and yet that there were pressures for parents to see their children as sexual. They suggest that the notion of sexual rights for this group might be idealistic rather than practical. No reference was made to gender, but it appears that from Swain and Thirlaway's discussion, that both men and women were perceived in the same way. This research raises issues that suggest that there might be a 'limit' to how far sexual rights can be claimed for this group, as well as the difficulties that might be encountered by parents in being able to see their children as sexual.

In 1999 Murray *et al.* also conducted research in the UK into staff attitudes towards sexuality and people with learning disabilities. They used questionnaires with 178 male and female employees across three organisations providing services to people with learning disabilities. Importantly, they found that 56% of respondents were not influenced by formal policies, and that direct-care staff had less liberal attitudes towards sexuality than the three other categories of respondents (health care; professional, including social workers, psychologists and therapists; and managerial). The authors suggest the need to bridge the gap between policy and practice, and better training for staff – particularly relating to attitudes. Such research has important implications in relation to the way in which services support people who have learning disabilities in

relation to sexuality. It suggests that staff attitudes might, potentially, have more impact on service users' lives than service policies, and that those working directly with service users might be the most conservative in attitude.

Christian *et al.* (2001), in the US, researched staff values in relation to the sexual expression of women with developmental disabilities. Their findings, based on forty-three surveys with men and women (mainly female), found that over 90% of respondents suggested that women with learning disabilities had the same sexual desires as those without disabilities, that sexuality was an important part of the lives of the women they worked with, and that these women should have the freedom and opportunity to express their sexuality. However, only half felt that service providers saw these women as 'sexual beings' (2001:286). Over 90% also felt that women with learning disabilities could enter 'successful' marriages or partnerships (2001:286). However, the severity of service users' impairments were considered, by approximately half of the respondents, to be influential on service users' ability to have sexual relationships, get married and have children. However, over 90% agreed that these women could be 'competent' mothers with support and training (2001:287). Interestingly, the authors found that staff's personal opinions tended to take precedence over service policy, and over half had not read their service's sexuality policy, or could not remember reading it.

These findings are interesting because they suggest, that in the US, and in relation to this study at least, the vast majority of staff agreed that it was important to support the sexuality of women with learning disabilities, challenging the notion that such staff continue to harbour stereotypical viewpoints in relation to women with learning disabilities' sexuality, or lack of it. One of its minor drawbacks, like other similar work, is its lack of focus on how men and women might differ in relation to supporting women with learning disabilities in this area of their lives.

McConkey and Ryan conducted research into staff experience (rather than attitudes) in Northern Ireland, in relation to dealing with what they describe as 'sexual incidents' (2001:83). Questionnaires were sent to service providers providing a range of services to men and women with learning disabilities (including education providers), with 150 responses. Only 22% had attended a course on sexuality, with only 11% of this

total representing direct care staff. Respondents reported that more attention was given to policy related to vulnerable adults. As the authors suggest, an emphasis on protection from abuse might result in staff seeing all sexual behaviours as 'risky'. Interestingly, staff felt least confident dealing with the break up of a relationship than 'unwanted sexual advances, same sex kissing and questions about contraception' (2001:85). However, as with other studies, gender was not explored.

Yool *et al.* (2003) explored the attitudes of staff working in a UK-based medium-secure hospital via interviews with four staff members. Whilst this study was extremely small-scale, findings confirmed that whilst staff held relatively liberal views towards masturbation, attitudes towards sexual intercourse, homosexual relationships and service user decision-making in relation to sexuality were less so.

In Australia, Cuskelly and Bryde (2004) looked at the attitudes of forty-three parents of people with learning disabilities, 84% of whom were mothers; sixty-two support staff, 68% of whom were female; and a community sample of sixty-three individuals, 59% of whom were female, and 33% of whom were university psychology students, in relation to the sexuality of men and women with learning disabilities. A questionnaire comprising an attitude scale was used. They found that older people were more conservative in their views than younger people, and that parents were more conservative than staff, who tended to be younger. Attitudes towards parenthood were less positive than attitudes towards other aspects of sexuality in relation to parents and staff, but the community sample did not see parenthood significantly differently to other aspects of sexuality. Nevertheless, Cuskelly and Bryde argue that responses show that all respondents viewed the sexuality of people with learning disabilities generally positively, although this does not represent their views in relation to the degree of impairment an individual might have since respondents were asked to comment as if the person had a 'moderate' learning disability. Further, respondents were not asked to keep a specific gender in mind when answering questions and so, as the authors suggest, attitudes in relation to gender were not reflected.

Parkes (2006) conducted two focus groups with staff from two services in the UK to explore their feelings about supporting people with learning disabilities, specifically in relation to sexuality. In total nine staff took part, predominantly women

(seven). The study showed that parental attitudes towards sexuality were perceived by staff to be prohibitive, and staff tended to avoid supporting service users to take risks to avoid conflict with parents who saw service users as vulnerable. Some colleagues were also perceived to be prohibitive in their attitudes, and focus group members expressed anger when service users' sexuality was denied. There was a mixed response to same-sex relationships, with some prejudice apparent. *Valuing People* (Department of Health 2001a) was criticised for not giving guidance on how to support service users' sexuality. This study gave a small insight into gender, where participants commented that it was more or less accepted that male service users would sexually harass others, underlining the notion that male sexuality might be seen as problematic. It shows that staff are willing to support service users' sexuality but reluctant to do so due to potential conflict with parents and because they feel that they need more support. It is also interesting to note that whilst focus group members themselves appeared to hold relatively liberal attitudes towards the sexuality of service users, they did not necessarily see their colleagues as holding the same opinions. This suggests that those who chose to take part in the research might have done so because they felt it was important to support the sexuality of people with learning disabilities. This further implies that similar research might not fully reflect the attitudes of all staff within services.

In an Irish piece of research, Drummond (2006) explored the attitudes of parents and staff involved in supporting people with mild-to-moderate learning disabilities within one major care-providing organisation. This was a larger-scale quantitative study based on postal questionnaires involving forty-five staff (ten male, thirty-five female). All respondents held relatively liberal attitudes towards people with learning disabilities having relationships; however younger respondents and those with a higher level of education seemed to be the *most* liberal. Although the gender and level of ability of service users did not seem to influence opinions, religion did – not surprisingly, however, given the influence of Catholicism in the area in which the study was conducted.

Moving on to studies that combine research with staff/parents, *and* people with learning disabilities, Heyman and Huckle's (1995) UK study into the meaning given to sexuality by men and women with learning disabilities, and their carers, shows that

many respondents, particularly 'informal carers', saw sexuality in terms of risk. Research was based on several interviews with twenty adults attending two day services over two years, with interviews with at least one informal carer from the interviewee's home (this seemed to be people from within the respondent's family), and with eight 'formal' carers at the two services. Follow-up interviews were conducted with seven adults and their informal carers. Informal carers saw the sexuality of adults with learning disabilities in terms of hazard. Women were perceived in terms of vulnerability, with men perceived in terms of threat. The adults with learning disabilities were seen as childlike and asexual, and of not being able to understand social/sexual morés, yet informal carers were reluctant for those they cared for to access sex education. Adults with learning disabilities referred to sex as 'rude', one woman reported that sex was 'painful' (1995:148), some referred to being prohibited from having sexual relationships, and only one referred to having had sex education, with television being cited as the most usual source of information on sexuality. Formal carers were not focused on particularly within the study, but apparently tended to see service users as being capable of greater autonomy than informal carers. Heyman and Huckle argue that despite the protectionist stance taken by carers, they should not be dismissed as 'overprotecting' their children. Instead, it is important to work with them to find ways of helping people with learning disabilities to have sexual autonomy. This study suggests that families continue to feel concerned about family members with learning disabilities' sexuality, and that paid staff might be more 'liberal' in outlook.

Löfgren-Mårtenson's (2004) Swedish research included participant observation at fourteen dances for young people with learning disabilities, and interviews with thirteen (male and female) youths and young adults with learning disabilities, thirteen staff members from a range of service settings, and eleven parents of young people with learning disabilities. She suggests that despite policy changes and the willingness to see young people with learning disabilities as sexual beings, staff and parents nevertheless act as 'institutional walls' (2004:206) because they do not know how to 'deal' with this sexuality. Löfgren-Mårtenson argues that the young people themselves expressed a positive attitude towards the possibility of having sexual experiences, and a small number towards parenthood, suggesting that the practices of parents and staff might not



impact too heavily upon this group. Löfgren-Mårtenson usefully highlights the way in which the lack of privacy afforded to the young people meant that sexual behaviour was exhibited in public, and that this then became labelled as 'abnormal'. Whilst she suggests that female carers held more conservative views on sexuality, Löfgren-Mårtenson does not describe how gender might have impacted on respondents' viewpoints and actions.

In relation to research that focuses *specifically* on the experiences of people with learning disabilities, Millard (1994) describes setting up a women's group (with women who had learning disabilities) on sexuality in the UK. She describes how the women who attended it were embarrassed to talk about the sexual parts of their bodies, and that they both lacked the knowledge and language to do so. The only words that respondents knew to describe their breasts or vaginas were ones they felt uncomfortable with. Further, the women felt shame in relation to their bodies, and 'felt the sexual parts of them were dirty and unpleasant' (1994:144). Additionally, they suggested that women did not enjoy sex, and that they were just being 'used' by men (1994:145). Respondents were deeply uncomfortable with particular images used in the sessions, particularly those of naked men. The authors found that this was due to the sexual abuse that some had experienced, and found that respondents valued the opportunity to 'talk and be heard' in relation to this subject (1994:149). This shows that women with learning disabilities can feel deeply unhappy about their bodies, and about sexuality more generally. The level of sexual abuse within the group suggests that this might be implicated in such views. The study highlights the importance to such women of having the space to talk about these uncomfortable sexual experiences, and the potential lack of opportunity to do so elsewhere.

In Belgium, Lesseliers (1999) interviewed forty-six people with learning disabilities about sexuality. The research focused on people's relationships and experiences of sex and sexuality. Like UK findings in the mid 1980s, these stories revealed a 'striking' lack of knowledge about sex. The research also highlighted the way in which institutions and group living played a part in respondents' experiences – especially in relation to the lack of room (both physically and symbolically) for sexual relationships to develop. Both sexes' accounts reflected a less than positive attitude

towards sexuality, and women in particular tended to be passive in sexual relationships, allowing a male partner to take the lead. Additionally, a lack of emotional and structural support appeared to exist within services.

Michelle McCarthy's research (1998a, 1999) perhaps represents the most significant piece of UK research into women who have learning disabilities and sexuality to date. It differs significantly from other studies in its focus on women, and its use of a feminist theoretical (rather than disability-related) framework<sup>15</sup>. Interviewing seventeen women with learning disabilities relatively broadly about their sexual experiences, she suggests that respondents lacked sexual agency (i.e. respondents deciding for themselves what they wanted to do, with whom, where and how, with men tending to take the lead in these matters), highlights the relatively high levels of abuse<sup>16</sup> within the group (although McCarthy accessed respondents through her work within services that provided information and support on sexuality and relationships, and this might have influenced these findings), and the way in which they experienced sexuality on a physical level, but did not *feel* sexual. McCarthy believes that the way in which people with learning disabilities are left out of mainstream culture or cannot access mainstream culture, and so cannot develop a sense that sex is 'special' contributes to this (McCarthy 1999). She also showed that respondents experienced a lack of choice and control over wearing/purchasing clothes, and that only one woman out of the thirteen women who were using contraception had chosen which method she used – parents, doctors and staff were cited as the people who had either chosen the method of contraception, or whether or not the women were using it at all (McCarthy 1998a).

More positively, long-term relationships were valued and positive, many of the women had resisted and recovered from sexual abuse, the women generally showed no embarrassment about traditional sexual taboos, and that despite potential resistance, they generally asserted their right to be mothers (McCarthy 1999). This piece of work – in

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<sup>15</sup> McCarthy feels that women with learning disabilities have more in common with other women than they do with disabled men.

<sup>16</sup> McCarthy highlights the different ways in which the term 'abuse' can be interpreted and suggests that what is defined as sexual abuse can include a range of sexual acts. McCarthy's own definition, 'any sexual contact which is unwanted and/or unenjoyed by one partner and is for the sexual gratification of the other' (McCarthy, 1993:282 cited in McCarthy, 1999:69) is useful. However, since such abuse might involve more than two people (the abuser and the abused), and that abuse might occur *without* sexual gratification (as aim or result), I would suggest that the definition 'any sexual contact which is unwanted' would describe my own definition for the purposes of this research.

my opinion – has paved the way for further exploration of more specific issues, such as how women with learning disabilities might relate to sexuality on an experiential/emotional level (*feeling* sexual) and the role of services in relation to this<sup>17</sup>.

However, McCarthy's work is also to some extent restricted, despite its broad scope, by the way in which she (deliberately) only interviews women who have had sexual experiences with others (who were all, although incidentally, men), and with her questions tending to focus on sexual activity<sup>18</sup>. Sexuality in this research context is therefore primarily about sexual practice or sexual relationships – although McCarthy clearly does not think that sexuality is reduced to these. As Richardson (2000) suggests, sexuality is constituted by practice, relationships *and* identity. I would suggest that sexual identity or a sense of sexual self can stand apart from practice and relationships; an individual can feel sexual, yet not have a partner or have sex, and as McCarthy herself suggests, can have sex and a partner, but not feel sexual. Additionally, although the impact of policy and services is referred to – particularly in the way in which sexual abuse within services takes place – McCarthy does not examine these in detail.

Johnson *et al.*'s (2002) Australian study, which focused on the life stories of twenty-five men and women with learning disabilities, showed that the attitudes of service providers and families made leading sexual lives and developing relationships difficult for respondents. They highlighted the lack of information on sexuality available, the lack of clear policies and guidelines for staff, and the loneliness and isolation that were features of respondents' lives. Families and service providers apparently ignored sexual or relationship issues, representing a 'silence' on sexuality, and some were prohibitive, for example one respondent reported her mother having told her that she could not marry her boyfriend because she only had one hand. Unfortunately this study did not account for the ways in which gender might have impacted on these respondents' experiences.

Wheeler (2007) conducted UK research with men who have learning disabilities, conducting two focus groups of participants drawn from a self-advocacy organisation,

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<sup>17</sup> Although her 1998a publication includes discussion about professional staff, the major description of McCarthy's research (1999) does not, focusing on respondents' relationships with men.

<sup>18</sup> McCarthy chose to interview people with whom she worked as a sex educator but does not explain why she interviewed only people who had had experience of sex 'with at least one other person' (1999:120).

and interviews with twelve men. Participants saw themselves as sexual (unlike the women in McCarthy's 1999 study), and as wanting marriage and children. However, they reported that they perceived a difference between themselves and others in the way in which they were treated. They felt that others were prejudiced against them and that they were not 'allowed' to take on particular roles, particularly in relation to having children. They had relatively positive views of male same-sex relationships but were less accepting of lesbian relationships. Few were employed, and many felt that they had little control over their leisure time. Further, they felt that leisure activities were limited, and impacted on any relationships that they had.

A focus in relation to sexuality has been on abuse. Peckham (2007) and Peckham *et al.* (2007) have, for instance, worked on sexual abuse, evaluating a UK survivors' group twenty-session pilot for women with learning disabilities. This showed that such sessions helped to improve sexual knowledge and reduce trauma for the women involved. The authors suggest that the sessions helped participants to 'move on' with their lives and argue for more such schemes. Other research on sexual abuse has included work by Sobsey (1994), Brown *et al.* (1995) McCarthy and Thompson (1996), and McCormack *et al.* (2005). All studies on sexual abuse suggest that such abuse is prevalent, but figures vary in relation to how they compare with those of the general population, and in relation to differences in experience between men and women (McCarthy 1999). Almost all references to the sexual abuse of people with learning disabilities refer to the way in which living in institutional environments put them at particular risk in comparison to the non-disabled population (see for example Sobsey 1994). Along with the work of Peckham (2007) and Peckham *et al.* (2007), Howlett and Danby (2007) have also published details on setting up a support group for women with learning disabilities.

Additionally, there have also been studies focusing on the development and implementation of sexuality policies within services, including Cambridge and McCarthy's (1997) study, which confirms other studies in that staff felt that sex was marginalised within services, and that more training and support was needed. Other work includes Stein and Brown (1995), Hames (1996), and Hogg *et al.* (2001), all who

looked at the effects of training on sexual abuse in relation to staff knowledge and attitudes.

Although Cambridge (1997) has highlighted the particular issue of HIV in relation to gay and lesbian people with learning disabilities, and the needs of gay men (1996a), very little research has been conducted into their experiences. One significant exception is the research conducted by Abbott and Howarth (2005). This research included interviews with seventy-one staff in twenty learning disability services across the UK about their views in relation to supporting gay, lesbian and bisexual people with learning disabilities, and interviews with twenty women and men with learning disabilities who were having, or wanted to have a same-sex relationship. Findings showed that staff did not talk about sexuality unless service users deliberately discussed it, staff had significant concerns about working in this area (due to lack of experience, lack of confidence, lack of policy and training, their own attitudes towards sexuality and fears over others' attitudes towards gay, lesbian and bisexual sexuality), and that services were heterosexist environments that also failed to meet the needs of lesbian and gay service users. They also showed that some respondents with learning disabilities feared 'coming out', that being labelled as having a learning disability and being gay, lesbian and bisexual was particularly difficult, some had felt discriminated against on the gay scene, that only a few respondents were currently in relationships, and that four out of the five who wanted to have children were dissuaded from pursuing this. Concerns were also expressed around the lack of privacy accorded to respondents with learning disabilities, and the way in which lesbian sexuality was 'hidden'.

This study, as well as highlighting the particular issues faced by gay, lesbian and bisexual people with learning disabilities, underlines a number of themes already seen in earlier studies in relation to heterosexual people as well as more particularly, women with learning disabilities. These include the way in which professionals see supporting service users' sexuality as problematic, and a lack of consideration for the sexuality of people with learning disabilities. Additionally, although the heteronormative (Warner 1993, Carabine 1996a, 1996b, Jackson 1996b, Richardson 1996, 2000) atmosphere within services is described in relation to its effects on gay and lesbian service users (suggesting that services continue to see sexuality within the confines of

heterosexuality), this heteronormativity has wider effects since whilst it ‘disciplines’ service users into particular normative sexual roles, it also disciplines them into normative gender roles (Richardson 1996).

Despite a lack of work in this specific area, it is encouraging to note that gay, lesbian, bisexual and transgender issues in relation to learning disability were explored in a number of articles in the *Tizard Learning Disability Review* in 2006<sup>19</sup>, suggesting that non-normative sexualities are beginning to be recognised and addressed within the learning disability field.

### *Sexuality and Disability*

Two wider studies into sexuality are worthy of mention. Shakespeare *et al.*'s (1996) research focused on the ethnographic accounts of forty-two disabled men and women in relation to sexuality. This research underlines the way in which sexuality has been ignored more widely in disability studies. It highlights the connection between disability and sexual deficit as well as the negative impact of segregation, lack of sex education, the overprotection and infantilisation of disabled people, and the failure of services to address sexuality. Whilst the authors admit that people with learning disabilities are not ‘adequately represented in our work’ (1996:12), it is nevertheless groundbreaking, and has not been followed up significantly since. Further, it highlights the way in which some of the issues highlighted in research into the sexuality of people with learning disabilities might apply to disabled people more generally: silence, overprotection, and the failure of services to address sexuality.

In relation to gender, Gillespie-Sells *et al.* (1998) explored disabled women’s sexuality, specifically black, lesbian and heterosexual women’s sexuality, in the UK. The study included the use of questionnaires (181 returned), interviews (numbers not stated) and a small group seminar of nineteen participants. Findings show common themes between the three groups: including the way in which they had been constituted as not sexual, and had been discouraged or not ‘allowed’ to get married or have children. Fifty-eight percent did not have children, although 35% wanted them, and 41% were not

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<sup>19</sup> Tizard Learning Disability Review (2006) 11:2.

in a relationship at the time of the research. Findings also showed that they lacked sex education (and 40% wanted more sex education), had little opportunity to socialise, that abuse was common, and that they had few role models. Further, black and lesbian women experience discrimination on different levels, and within their marginalised<sup>20</sup> groups, highlighting the view that disability is not experienced in the same way by everyone. Despite this, and the fact that it does not explore the experience of people with learning disabilities, it echoes (like Shakespeare *et al.*'s 1996), some of the themes emerging from research with this more specific group.

### *Learning Disability, Disability and Gender*

Very little empirical research has been conducted in relation to women and learning disability, irrespective of sexuality, with McCarthy's work (1998a, 1999) an outstanding example, alongside Peckham (2007) and Peckham *et al.*'s (2007) work on sexual abuse, Millard's (1994) with a women's group, and Christian *et al.*'s US study into staff attitudes. Of those studies *not* focusing specifically on sexuality, work focusing on women with learning disabilities has included themes of subjectivity (Scior 2003), self-harm (Downie 2001, James and Warner 2005), challenging behaviour (McKeown *et al.* 2003, and Wilcox *et al.* 2006 in relation to differences between men and women), the menopause (McCarthy and Millard 2003), menstruation (Rodgers *et al.* 2006), and cervical screening (Broughton and Thomson 2000, Wood and Douglas 2007). Traustadóttir and Johnson (2000) have also produced an edited book of women with learning disabilities' accounts in relation to their everyday lives.

Scior's work on gender (2003) is particularly interesting because of the ways in which it highlights the impact of a number of gendered discourses that also, I would suggest, interact with heteronormative discourses on the lives of her female respondents. Scior interviewed five women in the UK about gender and sense of self and found that a number of specific gendered discourses were apparent in respondents' viewpoints.

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<sup>20</sup> By 'marginalised' I refer to those groups or individuals who do not represent 'the norm', including disabled people. This, however, is contextualised: disabled people might be marginalised within a mainstream society, but women and people with learning disabilities might be marginalised within the disabled community.

Specifically gendered discourses included seeing men and women as ‘essentially’ different, holding notions of romance in relation to (hetero)sexual relationships, and seeing themselves as ‘victims’ in relation to men and sexual abuse, with these countered by viewpoints that reflected feminist discourses. In relation to disability, a ‘guardianship’ (or protectionist) discourse was apparent, with respondents, for example, suggesting that they could not have children, and feeling themselves, or being seen as ‘childlike’ and asexual. Although there is evidence of a feminist discourse within these accounts, Scior argues that the intersection of gender and disability had negative consequences for these women, particularly in relation to their experiences of abuse. Whilst Scior does not refer to heteronormativity, it is clear that she sees gender and (hetero)sexuality working in less than ideal ways in these women’s lives. Whilst this research has brought some interesting insights into how women with learning disabilities see and experience their lives, it is an extremely small-scale study. Further, similar, research would help to explore such issues further.

It is interesting to note firstly, that the work on gender, other than the work of Scior (2003) and to some extent the work of McCarthy (1998a, 1999), tends to address issues around abuse and/or self-harm, or gynaecological issues; and secondly that work on men almost exclusively focuses on sexual offences (e.g. Green *et al.* 2002, Robertson and Clegg 2002, Lindsay *et al.* 2004, Courtney *et al.* 2006, Lunskey *et al.* 2007). This appears to represent a slight shift from the eugenic focus on *women* as sexually dangerous (Walmsley 2000). Cambridge and Mellan (2000) have highlighted this issue in particular, arguing that a focus on what they call the ‘pathological’ aspect of men’s sexuality leaves their wider sexuality ignored. Whilst women are often framed as dangerous sexually, it appears that men, in the research context, are almost entirely framed as physical threat. In relation to women, it appears that concern surrounds their apparent vulnerability to abuse, rather than their agency (sexual or otherwise).

Two wider studies on disability and gender, aside from the work of Gillespie-Sells *et al.* (1998), give some context to the more specific studies about men and women with learning disabilities discussed here. Lonsdale (1990) interviewed twenty-two women with physical impairments in the UK. Lonsdale argues that whilst the role of lover, mother and housewife might disadvantage women generally, those who cannot



take on this role are stigmatised. Respondents had issues with self image, felt invisible (they did not have a 'voice'), and were constituted as passive and dependent by the lack of services available to them. Disability was related by the women to a lack of control, with families, school, work, professionals and the general public assuming this control on their behalf. Morris (1989) focused on women's experiences of paralysis, using data from 205 questionnaires. These showed that respondents were assumed to be asexual, had problems with self image, and lacked information on contraception, thus reinforcing Lonsdale's (1990) findings, as well as some of the findings in relation to women with learning disabilities.

To conclude this section then, it seems that a number of consistent themes emerge from the research conducted so far. These include:

- a lack of sexual knowledge amongst men *and* women with learning disabilities
- sex education, where it is provided, is on an *ad hoc* basis
- some parents are more liberal in attitude towards the sexuality of their adult children, however, parental fears in relation to this persist for a significant number
- despite the more liberal attitude of staff towards the sexuality of people with learning disabilities (than parents), service users' sexuality is still perceived as problematic to deal with
- parenthood is deemed to be particularly problematic, both by parents/staff and disabled respondents (who are aware of others' attitudes towards this, but who might, nevertheless, wish to become parents)
- the level of an individual's impairment affects others' attitudes towards their sexuality, and whether or not they can cope with that, particularly in relation to parenthood
- people with learning disabilities are sometimes cast as 'eternal children'
- a lack of specific policies or training in relation to sexuality make it more difficult for staff working with people who have learning disabilities to support them in relation to sexuality
- failure of some staff to follow policies where available, and mixed responses by staff to client sexuality

- sex is constituted as a ‘private issue’
- sex is nevertheless something that is ‘managed’ or ‘policed’, with people with learning disabilities subject to what might be seen as overprotection and control, and an attendant avoidance of supporting people with learning disabilities to take risks
- people with learning disabilities are not accorded privacy – they have neither the physical nor emotional space in which to conduct relationships
- mixed responses to same-sex relationships by people with learning disabilities

Despite the literature spanning twenty-five years, there appears to be relatively little consistent change in relation to these themes. Other studies suggest the possibility that:

- women are ‘disciplined’ into particular gendered roles in relation to sexuality
- women with learning disabilities do not have positive experiences of sexuality, and are not necessarily sexual agents
- services are largely heteronormative environments
- age and education impact on the way in which staff perceive client sexuality, as does the kind of job they have (for instance managerial in comparison to staff providing direct support)
- men feel more sexual than women, but face the same prejudices and prohibitions

Returning to the focus of my own research topic, it is clear that firstly, relatively little work has been done on sexuality and learning disability, or gender and learning disability. Secondly, this research has been limited for a number of reasons. These include its tendency to focus on sexuality *or* gender, thus obscuring how each, whilst being analytically different categories, nevertheless affect each other (Butler 1999, Jackson 1999, Richardson 2007). The theoretical frameworks that have been utilised have also been relatively limited to disability-related ones. I would argue that those exceptional works that use feminist theoretical frameworks (like McCarthy 1998a, 1999) have produced more nuanced findings than those using disability-related frameworks, and in part I would suggest that this is because they look beyond disability or service

structures as the most or only influential factors in respondents' lives. A final limitation is the failure to recognise or question the kinds of social norms that are entangled with sexuality, gender and learning disability that has been flagged up by writers such as Brown and Smith (1992), Brown (1994), and Williams and Nind (1999), other than in a handful of cases (and most notably by Scior, 2003).

I would suggest that this study will take forward understandings of sexuality for women with learning disabilities, particularly in relation to how they feel about and give meaning to sexuality, and the role of certain social institutions in relation to this.

## **Key Concepts**

Throughout the thesis I will be referring to particular concepts and terms that need further explanation. I will discuss these here.

### *Discourse*

Although discourse has been described in a number of ways, my use of it is taken from the work of Foucault. Foucault sees discursive practice as

...not to be confused with the expressive operation by which an individual formulates an idea, a desire, an image; nor with the rational activity that may operate in a system of inference; not with the "competence" of a speaking subject when he constructs grammatical sentences; it is a body of anonymous, historical rules, always determined in the time and space that have defined a given period, and for a given social, economic, geographical, or linguistic area, the conditions of operation of the enunciative function. (1969:131)

Thus, discourse is not objective, neutral, or universal, it is subjective, normative and contextually specific. Thus, we do not have universal, value-free 'knowledge'. To take the point of 'sexuality', there is no one understanding of what it is; we have a multitude of 'knowledge(s)' that describe sexuality in different and sometimes competing ways, some of which become 'fixed', hegemonic and normative.

### *Disability, Learning disability and Impairment*

Disability and learning disability are, for the purposes of this thesis considered to be social constructs, a construction that will be discussed further in the next chapter. As Oliver and Barnes (1998:14) have argued, categories used in relation to disability have been ‘...frequently vague, malleable and used interchangeably.’ ‘Learning disability’ is thus a historically contingent concept (Nunkoosing 2000) that has been described in different ways at different times according to administrative purposes (Beadle-Brown *et al.* 2004).

In this thesis I do however refer to the fact that some people have been ascribed a distinct label ‘learning disability’<sup>21</sup>. By learning disability I *do not* refer to ‘learning difficulties’, a category that is used more broadly within education legislation (Department of Health 2001a), and which tends to include people with dyslexia for example. I mean those who have previously been labelled as ‘mentally handicapped’ (Doyle 2000), as my interest is focused on this specific group, who have experienced very particular institutional arrangements, as I have described. Despite this I acknowledge that ‘learning disability’ does not necessarily refer to a discrete, easily-identified group, particularly when comparing this label to the international context where different terminology is used. When looking at the wider literature the use of different terms by different writers, for example, makes comparing studies difficult. Thus, when using other people’s work as a reference, I have tried to ensure that despite labelling differences, their work has been as comparable as possible to mine, and have indicated where this is not the case, maintaining the term ‘learning disability’ to avoid confusion.

Whilst, like Goodley (2001), I have difficulties with the label ‘learning disability’, I have resisted using labels like ‘intellectual impairment’ or ‘cognitive impairment’ (that might be less stigmatising) on the basis that I am primarily examining the *label*, not the *impairment*. I also refer to the social model’s distinction between ‘disability’ (and in this case ‘learning disability’, in line with my definition of it as a label or category) and impairment. This distinction describes disability as a social

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<sup>21</sup> At times in the thesis I refer to the ‘label’ ‘learning disability’. I am not using the term ‘label’ in terms of ‘labelling theory’, simply as a practical term that ‘makes sense’ when describing learning disability and its relationship with people.

categorisation based on what might be perceived to be an individual impairment<sup>22</sup> (Oliver 1990). This is explored further in Chapter Two.

Additionally, whilst I briefly considered the notion of ‘difference’ rather than ‘learning disability’ as a central factor, I realised that the label of learning disability might have effects that differ to those experienced by others who might be labelled ‘different’. When referring to respondents as having a ‘learning disability’, it is on the basis that they have, for one reason or another, been labelled in this way by others, and attend an organisation that provides services for those with this ‘learning disability’ label. Most respondents, for example, referred to others, mainly staff who worked with them within residential learning disability services, having informed them of the courses available at the organisation where the women’s group met, or of the existence of the women’s group itself. Thus, being labelled as having a learning disability, and using one particular kind of service for this group (residential), led to respondents using other such services. Whilst some respondents denied the label of ‘learning disability’, their attendance at this organisation, and the way in which they were directed by others to it on the basis of their ‘learning disability’ label, made them ‘appropriate’ research respondents.

### *Sex; Sexuality; Relationships*

Wellings *et al.* (1994) highlight the difficulties in defining different aspects of sexuality, particularly when conducting research. Weeks (1989:1) has argued that: ‘the usual assumption is that sex is a definable and universal experience, like the desire for food...’ and that this ‘ignores the great variety of cultural patterns that history reveals, and the very different meanings given to what we blithely label as “sexual activity”.’

Defining my own meanings in relation to sex, sexuality and relationships, as well as working with the meanings respondents gave to them, has been a problematic task.

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<sup>22</sup> However, impairment, it has been argued, might also be described as a social construction (see for example, Thomas 1999, Tremain 2002). As Thomas (1999:8) has suggested, “‘impairments can be understood to be those *variations* in the structure, functions and workings of bodies which, in Western culture, are medically defined as significant abnormalities or pathologies.’ Thus, when I talk about the way in which disability has been ‘created’, it is made possible through the categorisation of impairment. For the purposes of this thesis, however, I use the term ‘disability’ to avoid confusion.

Additionally, whilst I wanted to describe an 'intimate' or 'sexual' life, I had difficulties in defining exactly what an 'intimate life' or 'sexual life' might be. Sex can mean any number of different things including penetrative (usually heterosexual) sex, procreative sex, and sexual identity/'orientation' (including being a 'man' or 'woman'. For the purposes of this study, I use the term 'sexuality' loosely to refer to sexual acts, behaviours, identities, relationships, thoughts, feelings and desires (Cornell 1995, 1998, Scott and Jackson 1996, Richardson 2000). As Scott and Jackson (1996:2) suggest:

...sexuality is not limited to 'sex acts', but involves our sexual feelings and relationships, the ways in which we are or are not defined as sexual by others, as well as the ways in which we define ourselves.

I use the term 'sex' to refer more specifically to sexual acts, although this term too is used relatively loosely, and does not refer to *particular* kinds of acts. Whilst I asked respondents to define 'sex' for themselves, responses tended to vary *within* interviews between sex as procreative (having a family), to sex as a male/female (perhaps penetrative) sexual act. Meanings associated with sex tended therefore to change; usually depending on the kinds of questions they were being asked. Thus, whilst my meaning of sex is usually 'open' (and I try to be explicit when I am not), in relation respondents' meanings I try to convey *their* meanings wherever possible.

Additionally, whilst I refer to 'relationships', the nature of these relationships are sometimes blurred, for example, one respondent referred to a boyfriend in her first interview but called the same man a 'friend' in her second interview. Additionally, not all women in relationships had what they described as sex with their partners, for example one respondent was married for ten years without, she said, having sex. Throughout I have attempted to give these relationships meanings that seemed appropriate, given the information I was given by respondents and/or the meanings that respondents gave to them themselves.

My use of the term 'intimate life' is an attempt to describe the way in which relationships might include kissing and closeness for example but not necessarily more 'sexual' acts (such as penetrative sex). The term 'sexual life' is an attempt to describe the way in which sex might be a part of an individual's life, and might include a sense of

sexuality apart from having a relationship. ‘A sense of sexual self’ is an attempt to describe the way in which an individual might feel themselves to be a sexual agent: it relates to how they *feel* in relation to sexuality; is it something they associate with themselves or not? Any reference to sexual identity relates not specifically to a sexual orientation and identification with it<sup>23</sup>, but with a more general sense of sexual identity – as someone who sees themselves as ‘sexual’.

### *Choice; Agency; Autonomy; Constraint*

‘Choice’ can refer to the act of choosing (to choose, to have chosen), the right to choose/have choice, and range of choice. As suggested, the notion of ‘choice’ is central to Government policies in relation to people who have learning disabilities. However, this notion of ‘choice’ has been problematised as an illusion. For example, the quasi-marketised services that represent the current mixed economy of welfare, as well as the service principle of normalisation – both ‘offering’ supposed choice, are contextualised within neoliberal frameworks. Burton and Kagan (2006:305) have suggested that choice is ‘elevated to a position above other goods’, a stance that ignores the difficulties that those with more severe impairments (a group whose experiences they argue are ‘glossed over’ by *Valuing People*<sup>24</sup>) might experience in negotiating such choice.

Whilst I too, am wary of the notion of choice, I have used the term in two ways within the thesis. The first is in relation to the way in which services refer to choice, and inherent within this is my critical stance in relation to it. The second is in a practical way to describe how respondents experience decision-making in everyday contexts – whilst ‘choice’ is a problematic concept; it is, nevertheless, something which respondents (as well as others) would perceive as ‘real’. In relation to the notion of ‘choice’ I also refer to ‘agency’, autonomy’ and ‘constraint’: by agency I refer to the ability to act (and for example make choices), by ‘autonomy’ to the freedom or independence to act (or make choices) and ‘constraint’ to the restriction of choice, agency or autonomy.

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<sup>23</sup> I use the term ‘orientation’ in terms of its ‘everyday’ use, but am aware that its essentialism can be challenged.

<sup>24</sup> Department of Health 2001a.

### *Sexual Rights*

Rights are central to the way in which services are provided to people with learning disabilities, and whilst the notion of rights is not explicitly a focus of this study, it underpins it, and the institutional context within which the study takes place. However, what 'rights' might mean more generally, is to some extent contested.

Rights are often described in terms of their relationship with citizenship: with civil, political and social rights comprising citizenship (Marshall 1950). Drake (1999:41) describes citizenship as being '...able to take part in the decisions that create or re-create the contours of a society, and to be able to participate in key functions such as work, leisure, political debate, travel and religious observance.' Drake highlights, however, how access to this status is unequal, with Borsay (2005) criticising Marshall's conceptualisation of citizenship for failing to take account the effects of gender, disability and ethnicity. Conaghan and Millns (2005:2) similarly criticise the notion of rights, suggesting that:

...their abstraction and universalism...tends inevitably towards a perpetuation of women's exclusion, a failure to acknowledge difference and a lack of recognition of the diversity of women themselves.

Thus, rights are not available to all, equally (Richardson 2000).

Further, how citizenship is interpreted shifts over time. For example Borsay (2005) highlights how the Conservative Government of 1979-1997 shifted the notion of citizenship from one of entitlement to one of contribution ('rights and responsibilities', particularly in relation to the obligation to work), and Borsay, as well as Drake (1999), has highlighted the way in which it has also been linked to consumerism, with power 'limited to a particular set of predefined choices or even merely to the expression of preference' (Drake 1999:43). Burton and Kagan (2006:310) suggest that an:

increasingly dominant model of human rights prioritises individual market choices and the option of casting a vote for one of several pro-capitalist parties, at the expense of rights to health and well-being, education, political, civic and



cultural participation...the notions of what people need, of what their rights are, have perhaps become distorted by this neoliberal shift in thinking.

In addition, as Shakespeare (2000a) has pointed out, and with particular reference to this study, sex is now central to consumption: 'As individuals, we demand the right to be sexual and to be able to choose whatever form of sexual expression or fulfilment we can find.'

Nevertheless, it is important to note that what constitutes 'sexual rights' might also reflect and enact particular cultural norms: and thus, apparently 'acceptable' sexualities might be more likely to be seen in terms of rights than other less 'acceptable' ones. For example, heterosexuals can marry but gay and lesbians cannot (UK 'civil partnerships' are not the same as marriage).

It is also worth pointing out that citizenship is implicitly linked to adulthood (Thompson 2005), and the historic denial of citizenship to people with learning disabilities may also be linked to their perceived less-than-adult status. In addition, the parental rights of people with learning disabilities have been (and are) tempered by tension between the right to have a child, and the rights of children to care and protection (Painz 1993).

### *Formal Institutions*

By formal institutions I mean bodies who organise and/or provide care and support to people with learning disabilities in residential and non-residential settings, and who may be local authority social service, voluntary or private organisations. When I use the term in relation to formal services I make this explicit. As suggested, formal service settings in this study refer to a range of services, and again I attempt to be explicit in relation to what these might be. Services referred to include college courses (I refer to courses specifically for adults labelled as having learning disabilities), day services (here referring to segregated facilities providing courses and support for people labelled as having learning disabilities) and residential care. Residential care facilities referred to include larger residential facilities (here I mean facilities of seven or more residents), small group homes (by this I mean homes with up to six residents), independent

supported living (as previously described), and family placement (where an individual with a learning disability lives with an 'adult carer' or 'adult carers', often couples, perhaps with others who have a learning disability, as if they are a family.)

When using the term 'institution', I also refer to the way in which particular social arrangements, *including* the formal institutions/services described, act as a means of regulating individuals and groups of people, and how such social arrangements, and the regulation explicit and implicit within them, become institutionalised. Within this chapter and the next I explore how formal services might act to regulate women with learning disabilities in relation to social norms.

### *Family Institutions*

This thesis also explores another institution, the family. Like formal institutions, I suggest that family institutions can act to regulate individuals within them. For example, family and the associated institution of marriage can serve as both a product of regulation (with marriage for instance regulated by state and/or church) and as a site of it (where, for instance, regulatory male and female heterosexual and gendered roles are, or can be, 'played out').

Whilst there have been great changes in family institutions in recent years<sup>25</sup>, the extent to which such 'new' forms of living neutralise the regulatory power of marriage and family is debated. Women's roles for example, whilst changing in some ways – with greater access to paid work outside of the home, also show consistency – women still earn less than men (Jackson 2007) and still take on the majority of household tasks and caring roles within the home (Giddens 2001, Jackson 2007). In addition, the ideology of a traditional family 'retains a strong hold on the collective imagination' (Jackson 2007:129) with 'newer' forms of family and relationships less challenging to these than immediately apparent. For example, gay and lesbian civil partnerships whilst seen by some as an acceptance of new forms of partnership, have also been critiqued for the way in which they might serve to legitimate and normalise particular kinds of relationships

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<sup>25</sup> For instance, less people are marrying (Lees 1993, 1997, Wellings *et al.* 1994, Jackson 1997, Walby 1997, Giddens 2001, Jackson 2007), there are more lone parents (Giddens 2001), and there has been a corresponding rise in new forms of family, including 'families of choice' (Weeks *et al.* 2001).

over others (i.e. those that most conform to, or emulate, heterosexual relationships) (Weeks *et al.* 2001, Richardson 2005). Thus, for the purposes of this thesis, the family is seen as an institution that despite social changes, continues to act as a strong regulatory force in people's lives, both in terms of what it represents and (re)produces, but also in terms of the influence that family members have on each other within such frameworks.

Whilst family institutions and formal institutions are both regulated, (through, for example, marriage laws in relation to families, and care standards in relation to formal institutions), and whilst both also regulate in relation to how they operate, I would argue that formal institutions are more likely to do this in more formal ways, via their aims and objectives, policies and procedures. Of course, both institutions regulate via micro practices: the social interactions between individuals and groups that reflect and reinforce, or challenge, social norms. I elaborate on this in Chapter Two.

## **Chapter Outlines**

In this chapter I have attempted to situate the research. Chapter Two outlines the key conceptual and theoretical frameworks that have underpinned this study. Using Foucault's work on regulation and normalisation, and the social model of disability, I show how learning disability can be understood as a socially-produced 'medical' category, and how this process of categorisation enables and allows for 'expert' intervention, and regulation, in the lives of people with learning disabilities. I then discuss the way in which sexuality is also socially constructed, drawing on Foucault's argument that sexuality is socially 'produced' within regulatory frameworks, as well as symbolic interactionist work that suggests that sexuality is 'learnt' and given meaning via everyday social interaction. I conclude this chapter by briefly examining the concept of gender, and explore the ways in which women with learning disabilities might be subject to specific disciplining and regulation within normative frameworks relating to gender and learning disability.

In Chapter Three, I focus on the methodology that underpins the research. I briefly discuss the epistemological concerns underpinning the research, particularly my interest in trying to represent the 'voices' of a previously under-represented group. I also

discuss the methods used in the research: focus group, interviews, and participant observation. I look at issues related to access, sampling, development of the topic and interview schedules, and analysis. I explore some of the ethical issues involved in researching with women who have learning disabilities, as well as some of the difficulties I faced in exploring sexuality with this group.

Chapter Four is the first of three chapters that explore the data emerging from the research. It focuses on the accounts of sexuality, and sexuality in relation to learning disability, within institutional contexts. I look primarily at respondents' perceptions of accounts within family and residential service settings. I also briefly refer to how respondents developed understandings of sexuality within school and college settings, and through the 'doing' of sexuality and relationships. I also include some of my observations in relation to a course on sexuality that over half of the focus group and interview respondents had attended: the *Sex, Love and Relationships* course. Whilst some respondents suggested that they had been told little about sexuality within institutional settings, I show how these contexts are sites in which sexuality is in fact given very particular meanings, and such meanings tend to relate to discourses that suggest that sexuality is 'not for' women with learning disabilities, or to discourses that are regulating, and normative.

Chapter Five moves to look at the practices within family and service settings that impact on, or have the potential to impact on, the sexual lives of women with learning disabilities. These practices, which appear in many ways to mark women with learning disabilities as 'different', and to constrain the choices that respondents can make and the lives that they can lead, often serve to underline the largely normative accounts described in Chapter Four.

In Chapter Six I move back to looking at sexual accounts, and describe the meanings respondents gave to sexuality themselves. I highlight the apparently normative discourses reflected in respondents' accounts that seem to mirror those they hear in institutional environments, as well as some of the differences between these accounts. I also explore respondents' sense of themselves as women with learning disabilities, and how this impacts on the way in which they might see themselves as women, and as sexual actors. I suggest that discourses of prohibition and 'difference' based on a

learning disability 'master identity' exist alongside mainstream gendered accounts, and that there appears to be some congruency between institutional accounts of sexuality and respondents' own.

Finally, in Chapter Seven, I draw together some conclusions about the research. I highlight the ways in which the findings confirm how women with learning disabilities are constrained in relation to sexuality. However, I argue that the gendered and sexual norms significant in respondents' accounts act to potentially *reduce* autonomy, *and* act as indicators of 'adulthood' and 'womanhood'. I also interrogate my methods, as well as the limitations of the study described, and the difficulties involved in conducting it. I conclude by suggesting some possibilities for further research.

## CHAPTER TWO

### Conceptualising Learning Disability, Sexuality and Gender

#### Introduction

In this chapter I will conceptualise learning disability, sexuality and gender, drawing from a range of theories and concepts located within different disciplinary fields, which nevertheless inform my broadly sociological approach to understanding the ways in which the respondents described in this study construct meanings around sexuality. These frameworks represent a ‘toolbox’ approach (Corker and Shakespeare 2002): they do not form a single or necessarily cohesive theoretical framework but illuminate particular aspects of the research. Key work includes that of social model theorists from within the field of disability studies (particularly the work of Michael Oliver, 1990), the cultural and poststructural work of Michel Foucault (1973, 1989, 1990, 1991), and that of symbolic interactionists such as John Gagnon and William Simon (1974) and Ken Plummer (1981, 1995). The key concepts and theories drawn on here describe how we might conceptualise ‘disability’, ‘learning disability’ and ‘gender’ as socially constructed and regulated categories, and how sexual meaning might be constructed within normalising (Foucault 1973, 1989, 1991) frameworks.

I will begin this chapter by exploring some of the ways in which disability has been conceptualised, and how learning disability can be described as a social construction rather than a medical and individual ‘problem’ (Finkelstein 1980, Oliver 1990). I will argue that ‘disability’ has been the focus of specific regulation due to this categorisation, and a regulation that is effected in part through the service principle of normalisation<sup>26</sup>, as well as through other institutional practices. Central to this thesis is the question ‘what meanings do research respondents (women labelled as having learning disabilities) and those around them (their ‘significant others’) give to sexuality, and to sexuality in relation to gender and learning disability?’ I will therefore move on to explore the ways in which sexuality is itself constructed (or ‘produced’) and regulated,

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<sup>26</sup> As described in Chapter One.

through everyday accounts that reflect and reinforce wider normative discourses. I will conclude this chapter by examining more closely how sexuality might intersect with learning disability, as well as gender.

### **The Categorisation and Regulation of ‘Learning Disability’**

Although there has been a call to explore the cultural influences on the construction of disability (Shakespeare 1994), as well its psycho-emotional aspects (Marks 1999, Thomas 1999, Reeve 2002, 2004), I would argue that the social model of disability, with its roots in a socio-economic explanation of disability (Oliver 1996, Priestley 1998), is particularly useful in gaining an understanding of the ways in which disabled people, and people with learning disabilities, have come to be the subjects of intense regulation, particularly over the last century. Although this model has its limitations, for instance its lack of attention to the differential experiences of disability (Shakespeare and Watson 1997), including on the basis of gender (Morris 1993b, McCarthy 1999, Thomas 1999) and learning disability (Goodley 2001), and its lack of attention to the historical and enduring prejudice that disabled people face (Shakespeare 1994, Priestley 1998), I argue that it nevertheless offers a useful ‘point of departure’ (Thomas 2004a:25) for understanding how disabled people are categorised and regulated in relation to social and sexual norms.

The social model of disability reconceptualises disability, describing it as a socially constructed category that forms a counterpoint to an individual, medical or tragedy model that describes disability in terms of personal tragedy, and individual psychology (Oliver 1990). As described in Chapter One, Finkelstein (1980) saw disability primarily as a product of Western capitalism, where impaired people, unable to play an economic role within an industrialised society, were forced into a state of economic dependency. This dependency led to social segregation through exclusion from the workforce, the development of asylums, and of medical understandings of disability and impairment: experts were able to define ‘disability’ in terms of ‘the norm’ (Finkelstein 1980, Oliver 1990). Oliver (1990:xiv) has thus described disability in terms of social oppression:

...all disabled people experience disability as social restriction whether these restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general public to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities.

As Oliver (1996) suggests, a line is thus drawn between disability (the experience of social and physical ‘external’ barriers), and impairment (the physical, mental or sensory limitations within the individual). Whilst this introduces an artificial split between disability and impairment, since both are in fact conceptually and experientially intertwined (French 1993, Crow 1996, Shakespeare and Watson 1997, Corker and French 1999, Thomas 1999 and Tremain 2002), this split allows disability to be reconceptualised as a *social category* that can be likened to gender, race, ethnicity or class (Thomas 2004b): to be disabled is to be disabled by society, not by individual impairment.

Although Foucault’s work has not dealt specifically with disability, Galvin (2006) has highlighted the way in which his work, with its roots, at least originally and in part, in Marxism, works with rather than against social model ‘theories’. Like Finkelstein (1980) and Oliver (1990), Foucault (1973, 1987, 1989, 1990, 1991) highlights the way in which classification and categorisation orders and differentiates people along particular socially-constructed norms. These norms are not ‘value free’, and act to define what is ‘acceptable’ or not through the construction of a normal/abnormal binary. Through a process of ‘normalisation’, ‘disciplinary procedures’ act to regulate people in relation to particular norms, and by ‘normalising’ or neutralising what are seen as abnormalities. This process does not operate through force, but through more indirect means; with fear, guilt or the desire to conform acting as influential factors. Regulation is therefore dependent on *self* regulation, with individuals acting in relation to social norms. This new mechanism of power is, Foucault argues, irreducible to law (or what he calls ‘juridico-discursive’ or ‘sovereign power’), is not held by right but by technique, not effected by the law but through normalisation (with the law operating *as* a ‘norm’), and not through punishment but through control (via surveillance or ‘policing’). This process is inevitably linked to power. However, power



is not linked to 'juridico-discursive' or 'sovereign power'. Its disciplining nature means that it operates as a 'dense web that passes through apparatuses and institutions' (1990:96), and as such operates beyond the state and within all social relationships. Thus, power is everywhere, although Foucault does accept that it can become 'sedimented' at particular points within the web he describes.

Disability has also been constructed through a 'normal'/'abnormal' binary (Abberley 1989). As Davis describes, 'disability is a function of the concept of normality' (1995:2): the concept of 'normality' makes 'disability' possible. Learning disability, and disability more generally, are therefore classifications based on their apparent *abnormality* – they are 'other' to the norm. As Lupton (2003:42) states: 'A body that does not function "normally" or appear "normal", that is confined to a wheel-chair or bed, is both visually and conceptually out of place.'

The apparent 'abnormality' of disabled people is often articulated through the construction of them as incapable of living 'normally', and as dependent on others to 'cope' (Oliver 1989, 1990). For example the Department of Health's (2001a:14) *Valuing People* White Paper, focusing particularly on the notion of 'ability', suggests that:

Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.

Thus, disabled people and people with learning disabilities are constructed as 'other' in part because they are unable to do particular things without others' help, a construction that obscures the fact that few people (disabled or not) act independently of others (Oliver 1989, 1990, Shakespeare 2000b).

Oliver (1989, 1990) argues that the association between dependency and disability is compounded by a range of factors including service terminology (for example the use of words like 'care' imply that disabled people need 'looking after'), professional/service user relationships (with service user cast as dependent upon professional 'carer'), and the role of charities in the provision of services (disabled people become the *objects* of care). Oliver argues that these practices create disabled

*individuals*: in other words many disabled people are socialised by these practices into seeing *themselves* as dependent. As Barton (1989:1) emphasises:

...disabled people have been subject to modes of socialisation, particularly with professionals, which have been fundamentally disabling. They constantly experience encounters with significant others which create dependency and helplessness.

The role of 'expert' in the categorisation of disabled people as 'impaired', 'disabled' and 'dependent' is crucial. It is the 'expert' who decides who is 'impaired' (and thus 'disabled' and 'dependent'). Foucault's concept of normalisation also relies on the notion of 'expert' knowledge (1973). This 'expert' knowledge is, for example, effected through the medical 'gaze' which has the power to label and define the norm, and those who fall outside of it. This 'gaze' is deemed to be scientific, and the norms that it defines to be 'truth', thus obscuring the way in which norms are in fact socially constructed and arbitrary. As suggested, normalisation is entangled with the operation of power, and so, scientific 'knowledge' and power work together.

Swain *et al.* (2003) have argued that 'expert' knowledge, and the power associated with it, has been involved in both the care *and* control of disabled people. The medical role in disabled people's lives is rarely questioned, but as Bogdan and Taylor (1994:15) suggest, 'labelling and testing provide a cloak of scientific legitimacy to social control and oppression.' These arguments reflect Foucault's normalising and disciplinary frameworks (Hughes 2005, Tremain 2005), especially since medical surveillance is a significant feature in disabled peoples' lives (Borsay 2002).

However, Foucault describes the way in which 'expert' power is not limited to the medical profession, but is exercised more widely within, for example, schools, prisons, and asylums (1973, 1989, 1991). Thus the 'expert' is anyone who has been recognised to have particular 'knowledge(s)'. In relation to disability, Chadwick (1996) and Helldin (2000) argue the role of 'expert' goes beyond the medical practitioners who diagnose, categorise and label people 'disabled', to include other professionals involved in disabled people's lives, including service providers and service staff. Whilst training given to service staff, for example, is seen as fundamental to the fulfilment of their role (Department of Health 2001a), such training also legitimises their 'expert' status. Thus,

Chadwick (1996) and Helldin (2000) argue that the ‘expert’ on disability is not the disabled or impaired person, but the ‘appropriately’ qualified professional.

This process also locates the professional at the centre of the norm. As Corbett and Barton (1992:139) ask, ‘whose normality is to be valued and emulated? The seemingly ‘natural’ arrangement whereby professionals are defined as both ‘normal’ and ‘expert’ leads to power differentials between services and service staff, and disabled service users. Such processes of regulation, normalisation (as in Foucault’s understanding of the term) and surveillance can be seen in a number of ways in relation to people with learning disabilities, including the monitoring of individuals via service records, and through the process of care planning<sup>27</sup>. They are also particularly evident within the service principles of normalisation, social role valorisation (SRV), and O’Brien’s service accomplishments (1989), that play a significant role in the principles underpinning service provision.

On an everyday level, the service principle of normalisation, SRV and O’Brien’s accomplishments explicitly emphasise the role of service staff in day-to-day practice, and in Wolfensberger’s formulation of normalisation sanctions staff power to impose change; ‘normalizing measures can be *offered* in some circumstances, and *imposed* in others’ (Wolfensberger 1972:28 cited in Perrin and Nirje 1989:224, Wolfensberger’s emphasis). The regulatory role of staff is reflected by Robbins (1990), who argues that they play a significant role in the ‘policing’ of people with learning disabilities’ sexuality, and by McCarthy (1998a), whose respondents were ‘disciplined’ in relation to the clothes they wore and the contraception that they used. It has also been suggested that staff in service settings sometimes take on a ‘paternal’ role (Craft and Brown 1994, Deeley 2002) that ‘justifies’ the protectionist and controlling stances that they take.

As outlined in Chapter One, the service principle of normalisation and social role valorisation have been used and discussed in ways that tend to ignore the differences between them, and the different articulations of normalisation itself (Flynn and Nitsch 1980, Brechin and Swain 1989, Perrin and Nirje 1989, Painz 1993, Wolfensberger

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<sup>27</sup> Care planning is the general process whereby the individual needs of service users are identified and (hopefully) met, and is associated with practices such as monitoring and evaluation. Although this is ostensibly for the benefit of service users in that it ensures that they are ‘appropriately’ cared for, it also makes them the subject of surveillance. As Traustadóttir and Johnson (2005) have highlighted, assessment can also represent control.

1999). Here I will attempt to make distinctions between the ways in which the service principle of normalisation and social role valorisation might operate<sup>28</sup>. I will argue nevertheless that they both serve to underline a normal/abnormal dichotomy (Oliver and Barnes 1998), and regulate people with learning disabilities in relation to this dichotomy

The service principle of normalisation is based on service aims to offer people with learning disabilities ‘ordinary lives’ or ‘ordinary living’ (Bank-Mikkelsen 1980, Nirje 1980, Rolph *et al.* 2005). Social role valorisation is based on the idea that if people with learning disabilities adopt socially valued roles, their ‘devalued’ status will change. However, Chappell (1992) and Dalley (1992) refer to the conservatism and moral authoritarianism inherent within both normalisation and SRV.

Taking the service principle of normalisation first, normalisation is based on ‘offering’ people with learning disabilities ‘patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society’ (Nirje 1980:33). This implies that a norm in relation to everyday living both exists, and is desirable, yet as Foucault argues, norms are socially constructed and as such are contingent. Further, these norms change according to context, and to whom they apply to, and as I will discuss later, particular norms are also associated with women and people with learning disabilities. Further, normalisation’s emphasis on what might be described as ‘regular’ (or the ‘norm’) threatens to make out-of-the ordinary lives a devalued choice, although I would also argue that such choice is relatively illusory in that it operates within normalising and neoliberal frameworks. Normalisation aims to provide ordinary lifestyles and is based on the recognition that many people with learning disabilities have been denied these. However, by defining and validating a norm, it potentially devalues those lifestyles that are outside of that norm.

Secondly, Wolfensberger’s formulation of normalisation (and his related theory of SRV) is particularly associated with normalising and disciplining processes because of ‘its focus on using normative means and on establishing normative behaviour’ (Perrin and Nirje 1989:224). SRV, through its suggestion that there are valued (‘normal’) social roles, and oppositional devalued (‘abnormal’) roles, implies that people with learning

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<sup>28</sup> I will not discuss O’Brien’s (1989) accomplishments on the basis that they represent an amalgamation of normalisation and SRV, and that my arguments in relation to these will also apply to O’Brien’s work.

disabilities are not valued as they are. For example Oliver and Barnes (1998) have argued that SRV actually *devalues* people with learning disabilities; by suggesting that they take on ‘valued roles’ it implies that the roles they already inhabit are *not* valued. Craig *et al.* (2002) argue that services that promote ‘normalness’ thus help to maintain the stigma attached to the label ‘learning disability’. Williams and Nind (1999:669) have called this a ‘cultural denial of learning difficulties.’

Morris has stated that, ‘one of the most oppressive features of the prejudice which disabled people experience is the assumption that we want to be other than we are; that is, we want to be normal’ (1991:34). There is an implicit assumption within the service principle of normalisation, at least in its original Scandinavian formulation, that a normal life is something that people with learning disabilities want. However, it is clear in Wolfensberger’s formulation, and within SRV, that the wishes of people with learning disabilities might not be central to the normalisation process. This is apparent when Wolfensberger states that ‘if impaired people were trim and in good physical condition, showed good hairstyling and grooming, wore tasteful jewelry, etc., then – *like it or not* – they would be more apt to be seen in valued roles...’ (Wolfensberger 2000:115, my emphasis). Thus, my criticism here is not so much that disabled people might want to be normal (although this takes place within normalising contexts, and as such this ‘choice’ is never free from particular social pressures that are often ‘hidden’, as I shall go on to discuss), but that we should neither assume that they do, nor, which would be worse, *impose* normality upon them. These approaches reflect the regulatory nature of normalisation, but more particularly SRV.

Further, within Wolfensberger’s formulation of normalisation, and SRV, emphasis seems to be placed on appearance rather than ‘actual’ habitation of socially valued roles. Wolfensberger suggests that devalued people can be helped by ‘reducing or preventing the differentness or stigmata that may make a person devalued in the eyes of *observers*’ (Wolfensberger and Tullman 1989:212, my emphasis). Similarly, within the Scandinavian concept, people with learning disabilities are to be ‘offered’ conditions of living ‘close’ to the norm (Nirje 1980:33). This suggests that the norm of ‘ordinary living’ might not be available to this group (only something ‘close’ to it). Therefore, it might be possible, as Williams and Nind (1999:660) argue, that ‘patterns of ordinary

living...become, less a right, more a means to an end of gaining status...in the eyes of others...the way people behave is likely to be assessed in terms of whether it puts their image at risk.' This shifts the aims of 'normality' onto the way in which people with learning disabilities present themselves. Here, *looking* normal or approximating rather than inhabiting 'the norm' seems central to normalisation's aims. Again, there is a sense that normality, although it can be 'copied', is not necessarily something that is achievable: it is perhaps cosmetic rather than 'real'.

As suggested, people with learning disabilities, through the expert-defined abnormal status they have been accorded, mark the boundaries of normality: by their 'outsider' status they define what others describe as 'normal'. This would imply that an 'insider' status might be impossible, and that whilst people with learning disabilities are asked to try and change their status in terms of their 'social value', it is possible that they will fail as long as they are labelled 'different'. Thus, normalisation's disciplining effects might not be to reconstitute people with learning disabilities as valued 'insiders', but to both construct and maintain, rather than break down, the normal/abnormal dichotomy (Oliver and Barnes 1998, Oliver 1999).

So far I have focused on the social construction of disability and learning disability, and some of the ways in which these constructions are intertwined with regulation, and Foucault's concept of normalisation. These conceptualisations situate the research within a framework that suggests that research respondents are constructed as having learning disabilities, a categorisation that makes them vulnerable to expert interventions that include disciplinary and normalising effects. Whilst members of this group are constituted outside of the norm, they might also be subject to processes that discipline them into particular norms, or an approximation of those norms. Norms operate in different ways (for example in relation to gender, sexuality and learning disability) and different contexts (for example different levels of services, the family, and society).

## **The Production and Regulation of Sexuality**

In this section I will focus on the way in which sexuality too has been described as a social construction. I will draw particularly on the work of Foucault (1990), as well as symbolic interactionists such as Gagnon and Simon (1974) and Plummer (1981, 1995).

Giddens (1992) describes what Foucault (1990) calls a 'repressive hypothesis' of sexuality. Discussing the work of Marcuse, Giddens describes how sexuality can be seen in terms of an 'expression' and 'freedom' that can be repressed by modern institutions such as the workplace, with its de-sexualisation of the body. Foucault argues against Marcuse's perspective however, suggesting that sexuality has not been *repressed* through various mechanisms of regulation, as has commonly been thought, but has been *produced* through a 'discursive explosion' (1990:17) and 'a steady proliferation of discourses concerned with sex-specific discourses, different from one another both by their form and by their object: a discursive ferment...' (1990:18). Thus:

...sexual austerity should be understood, not as an expression of, or commentary on, deep and essential prohibitions, but as the elaboration and stylisation of an activity in the exercise of its power and the practice of its liberty. (Foucault 1987:23)

From this perspective, so-called 'silences' in relation to sexuality can be seen as producing, rather than repressing, particular forms of sexuality. This means that the 'silenced' sexualities of women with learning disabilities also 'produce' and construct this group's sexuality as asexual and/or dangerous. This idea that sexuality is a 'production' both highlights its socially constructed nature, and introduces the idea that by saying nothing about sexuality, we are in fact saying *something*. By not talking about women with learning disabilities' sexuality, we are denying them a sexuality (constructing an *asexuality*) or suggesting that they do have a sexuality, but that it is somehow wrong, or taboo (or, perhaps, 'dangerous').

As described previously, Foucault's work challenges the notion that categorisation is value-free. In relation to sexuality, Foucault argues that by defining different types of sexuality, and ascribing different moral values to these, 'a norm of sexual development was defined' (1990: 36). As Rubin (1993) has highlighted, the marital and reproductive aspects of sexuality are the most highly valued in Western society, with homosexuality considered to be 'outside' of the norm. The way in which

such homosexuality is seen as 'abnormal', and heterosexuality as 'normal' to the point that these norms are seen as 'natural' and institutionalised (Jackson 1996b, Carabine 1996a, 1996b) has been described by Butler (1999) as the 'heterosexual matrix', by Rich (1993) as 'compulsory heterosexuality' and by others as 'heteronormativity' (Warner 1993, Carabine 1996a, 1996b, Jackson 1996b, Richardson 1996, 2000). Particularly hegemonic norms, as suggested, include the association of sex with marriage and monogamy (Carabine 1996a), and the notion that sexuality is 'naturally' or 'essentially' procreative. These norms also describe men and women as fundamentally and 'naturally' (or 'biologically') different: women are 'natural' nurturers (Hollway 1984, Giddens 1992, Carabine 1996a), who are passively the objects of the 'male gaze' (Giddens 1992)<sup>29</sup>, whilst men are 'highly sexed' and sexually 'out of control' (Hollway 1984, Lees 1993, Carabine 1996a).

Whilst these are the norms associated with the 'mainstream', it is interesting to note that disabled people, who are often cast as stigmatised 'other', appear to become further stigmatised when associated with *any* kind of sexuality, whether it is within the norm or not. As Galvin (2006:502) notes: 'When disability and sexuality intersect, the specific marginalisation that results takes one of two distinct, yet connected forms: the disabled person is categorised as "asexual" or "perverted".' Brown has argued that when people with learning disabilities, who are constructed as 'abnormal', have 'normal' sex, they are 'punished' for challenging the norm that says that sexuality is 'not for them', and, she argues are 'actually *breaking* the rules for their "kind", and should be supported in what is an act of rebellion rather than conformity' (1994:141, original emphasis).

It is also interesting to note that whilst people with learning disabilities are located as 'other' in relation to the norm, they might, nevertheless, be subject to disciplinary forces that are associated with the 'mainstream'. Therefore, women with learning disabilities, whilst cast as 'abnormal' in relation to sexuality, might still be subject to the same disciplinary forces as other, non-disabled women. This might still be the case whether or not they can actually achieve 'normality'. Returning to the service principle of normalisation and SRV for example, these principles appear to underscore

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<sup>29</sup> Of course, this is a simplified picture in that such norms are contingent on context. Women are also 'within' the norm when cast as more 'dangerous' than men for example.



particular sexual norms. Bank-Mikkelsen for example, representing the original Scandinavian version of normalisation, describes sexuality in the narrow terms of ‘mixed sexes and sexual life, marriage and children’ (1980:63). Similarly Nirje states that ‘normalisation...means living in a heterosexual world’ (1980:43). This offers people with learning disabilities a limited view of what personal and sexual relationships can be. As Williams and Nind (1999) argue, the service principle of normalisation therefore fails to recognise non-heterosexual lesbian identities and practices. Although the principle of normalisation is based on the need for people with learning disabilities to have the same rights as others, this reflects the way in which, as Bordo (1993) argues, agency is often exercised *within* normalising ‘structures’.

I would further argue that professionals, legitimised as having ‘expert’ knowledge and charged with the implementation of normalisation, have the potential therefore to influence the *kinds* of sexual accounts women with learning disabilities have access to. This might operate in both formal ways (what policy or normalisation say or do) and informal ways (what individual staff might say or do). Whilst normalisation or policy more generally might suggest that people with learning disabilities have a right to a sexual life, professionals might underscore different norms, including persistent and historical norms that imply that women with learning disabilities should not have a sexual life. This is underlined particularly in the empirical research literature, which suggests that staff hold mixed attitudes towards the sexuality of people with learning disabilities, with some finding it problematic (Robbins 1990, Murray 1999 *et al.*)<sup>30</sup>, and that some staff follow service policy in relation to sexuality, whereas others do not (Murray 1999 *et al.*, Christian *et al.* 2001). Staff and service practices also underline the idea that people with learning disabilities might not be sexual or have sexual lives, most evident through the lack of emotional space accorded to this group (Lesseliers 1999), the lack of training for staff or service policy in relation to sexuality (Robbins 1990, Murray 1999 *et al.*, McConkey and Ryan 2001, Johnson *et al.* 2002, Abbott and Howarth 2005) and the lack of physical privacy in which to have relationships (Lesseliers 1999,

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<sup>30</sup> None of the studies appeared to take the differences in how men or women might be perceived into account. Thus it remains unclear whether such attitudes are affected by the gender of service users.

Löfgren-Mårtenson 2004, Abbott and Howarth 2005). It is thus clear that the norms associated with sexuality are socially produced, but have tangible effects.

Moving back to the notion that sexuality is socially constructed, Foucault's conceptualisation of discourses, which is central to the way in which he describes the 'production' of sexuality, has been described by Harding as 'lived out, acted out and spoken by individuals' (1998:4). However, there is, nevertheless, a sense that these broad regulatory processes might be difficult to relate to the 'everyday'. Foucault's work has also been more broadly criticised for its lack of attention to gender (Sawicki 1991, Jackson 1996b, Richardson 1997, Harding 1998, Jackson 1999).

In some ways those working within symbolic interactionist frameworks have dealt with these particular factors that are, or seem, absent in Foucault's work. A symbolic interactionist approach frames sexuality, and the meanings associated with it, as constructed through the seemingly more 'grounded' micro-processes of everyday social interaction. In their early work, Gagnon and Simon (1974) discussed this in terms of sexual 'scripts'. Here, the individual constructs his or her sexuality from sexual 'scripts' which are learnt from everyday experiences and interactions: 'the doing of sex (even when alone) requires elaborated and sequential learning that is largely taken from other domains of life...' (Gagnon and Simon 1974:8-9). For example, kissing is not a 'natural' or even inherently sexual act, but we learn that it *is* sexual because society 'tells' us it is, and acts as if it is. Gagnon and Simon believe that *all* aspects of sexuality – including desire – are learnt and literally 'acted out', although not all those who argue that sexuality is constructed would go so far as to rule out a 'natural' sexuality. Fuss (1990) for example, has suggested that we view the sexual essentialism/constructionism argument not as a binary, but as a continuum. Gagnon and Simon (1974) further suggest that scripts are gendered, and so distinct male and female sexualities emerge. As suggested, these sexualities are associated with an active and sexual masculinity, and a passive and nurturing femininity. These ideas have been significantly taken forward by others, including Richardson (1997, 2000) and Jackson (1999, 2006). This notion of sexual scripts therefore places emphasis on the way in which we learn to be sexual, or learn *how* to be sexual, through what we see and hear: it is modelled to us by others, rather than 'natural' and 'innate'.

Plummer (1981) has also highlighted the socially constructed nature of sexuality<sup>31</sup>. One of the most useful terms he uses in relation to this is 'accounts'. Plummer argues that people connect their personal experiences to the 'accounts' available to them, 'a process of building identities throughout life through significant encounters' (1981:92). Like Gagnon and Simon's (1974) notion of scripts, accounts are therefore critical to the development of 'the self', and an understanding of sexuality more generally. However, this process is complex, and bound up with the way in which others seek to categorise us, and our interpretation of this. Gagnon and Simon's 'scripts' appear to be, though limited to what we encounter, freely taken up or not as our own, thus failing to recognise the effects of power (Jackson 1999). However, Plummer's analysis suggests that such a process takes place in relation to categories and *norms*: our 'choosing' of particular sexual accounts, and the way in which we give meaning to sexuality, is in a context within which we are positioned by others. Whilst Gagnon and Simon do acknowledge for instance that we experience things differently depending on how we are labelled, Plummer appears to be bringing in a deeper understanding of how this experience operates within power structures. Thus Plummer highlights the difference between *self*-identification with a category and being placed in that category by others, which links back to, and mirrors, Foucault's concept of regulation. As Plummer argues, the construction of categories and our placement within them is often motivated by political concerns which serve 'to order, control and segregate in the name of benevolence' (1981:53) that also render 'whole groups of people devalued, dishonourable or dangerous' (1981:53), and these statements can easily be applied to women with learning disabilities, particularly as reflected in eugenic thinking.

Importantly, Plummer points to the split between homosexual acts and homosexual identities, arguing that whilst people might engage in homosexual acts they need *not* identify with being gay. Conversely people might never engage in a homosexual act but *still* identify themselves as gay. Plummer therefore argues that 'homosexuality is a complex, diffuse experience that anyone may have' (1981:57). This differentiation between sexual acts and sexual identities is explored, for example, by

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<sup>31</sup> However, whilst Gagnon and Simon (1974) suggest that all aspects of sexuality are learnt, Plummer concedes that sexual orientation might be an innate characteristic.

Richardson (2000). The way in which acts and identities (or a sense of sexuality) are decoupled is central to this study. It suggests that whilst respondents might never have had sex (by their own definition), this does not preclude the fact that they might feel themselves to have a sense of sexuality, or a sexual identity (Richardson 2000).

Plummer's 1995 work *Telling Sexual Stories* discusses the notion of 'sexual stories'. These are

...simply the narratives of the intimate life, focused especially around the erotic, the gendered and the relational. They are part of the wider discourses and ideologies abroad in society, and they have much in common with all manner of other stories with differing foci – detective stories, travel stories, life stories, near-death stories. (Plummer 1995:6)

These stories, he argues, represent an explosion of interest in sexuality where once there was apparent silence.

Whilst Gagnon and Simon's (1974) 'scripts' are learnt via observation and are, in a sense, 'enacted', and Plummer's accounts (1981) seem more related to what we hear, his 'stories' acknowledge the way in which how we talk about sexuality involves what he calls 'story telling strategies' (1995:36). Thus, what is central to stories is their constructed and 'storied' nature. The way in which stories are constructed includes a process of 'bricolage': stories are constructed from a range of sources since 'the social order heaves as a vast negotiated web of dialogue and conversation' (1995:20).

Within this web he acknowledges the role of 'significant others':

Parents tell you what you were like as a 'baby', peers rehearse significant events of your school-days, a spouse reminds you what you were really like before marriage, a lover assembles your erotic nature in a sweaty post-coital talk. Again, none of this is *the life*, but is the very stuff for assembling the sexual biography. (1995:39)

These stories are therefore embedded within everyday social experiences and interaction, but can also be made 'public', in that such 'personal experience narratives' (Plummer 1995:15) are increasingly saturating the media. They are 'social actions embedded in social worlds' (1995:17). Localised stories are (as I would argue are

accounts or scripts) therefore contextualised within wider narratives, or in Foucauldian terms, discourses.

Plummer asserts that the meanings of stories are never fixed, but are produced by shifting interactions between producers and readers within shifting contexts. Thus, in relation to this study, it could be said that the research respondents hear, 'read' and interpret different meanings of sexuality, and within different contexts. For example, they might hear stories or 'accounts' of sexuality that shift and change within the same context and in the same social relationships, for example, within the family. Additionally accounts will differ, for example, between family, formal institutions and the media. Similarly, different generations of women with learning disabilities will hear different stories which reflect the very different cultural attitudes towards sexuality that have emerged over time (Haste 1994). Further, the way in which *respondents* give meaning to sexuality might also change in and between these contexts. Plummer's work, although not strictly poststructural, therefore reflects a poststructural understanding of how multiple meanings are constructed within shifting contexts.

Plummer (1995) argues that some sexual stories are marginalised. By this he means that certain accounts of sexuality, such as those of paedophiles, are not heard. Plummer suggests that particular stories can only be told at particular moments in history. Thus, the stories of child sex abuse victims have only been heard relatively recently, as have the stories of women with learning disabilities. Such stories, Plummer argues, act as both social *and* political processes. Like Foucault, Plummer recognises the process of power in relation to the way in which sexuality is constructed. Thus, sexual stories exist within a 'a stream of power' (1995:16) that nevertheless allows marginalised sexual stories to challenge the 'truths' of dominant ones once made visible. Through making visible the 'voices' of respondents in this study, hegemonic constructions of that group's sexuality, such as their apparent asexuality, might be contested with alternative stories or accounts. The work of the Crafts for example (Craft and Craft 1978, Craft and Craft 1979, Craft 1980, Craft 1983, Craft and Brown 1994), in relation to people with learning disabilities, represents the emergence of a 'new' sexual story and this study represents a further phase of that story. This aspect of Plummer's work will be returned to in the next chapter.

Social constructionist accounts therefore describe sexuality as something that is produced and regulated through social categorisation, and the changing meaning associated with those categories. It can be constructed both within everyday interaction (scripts, accounts and stories), or in wider more abstract ways (stories and discourses). Further, sexuality has multiple meanings associated with it that are shot through with normative values, and are open to contestation. Thus, competing discourses emerge, and in this thesis I explore the ways in which these might influence women with learning disabilities, and the way in which these women give meaning to sexuality themselves. This understanding of the construction of sexuality, both in terms of the meanings that we give to sexuality in everyday settings with significant others, such as family, service staff and peers, and in terms of the wider discourses these meanings might reflect and underscore, is therefore fundamental to the way in which I conceptualise sexuality within this thesis. Sexuality is not therefore a ‘natural’ phenomenon, that is freely expressed or not, but something that is constructed and regulated in multiple and contradictory ways.

Whilst ‘scripts’, ‘accounts’ and ‘stories’ are all relevant to the way in which I conceptualise sexuality within this thesis, I will refer most frequently to the notion of ‘accounts’. At times I do however refer to ‘scripts’, most notably where I refer to the process of learning about the ‘doing’ of sexuality, since the notion of ‘scripts’ and the ‘acting out’ of them seem relevant to this, and I also use the concept of ‘stories’ to underpin my methodology, as this emphasises the ‘storied’ nature of how we talk about our lives.

### **Bringing It All Together: Sexuality, Learning Disability and Gender**

In this final section, I would like to focus more particularly on the ways in which some of the theories and concepts outlined in this chapter might relate, specifically, to women with learning disabilities, and to the respondents involved in this study. Here I will also draw in the notion of gender, to explore how this might intersect with learning disability, sexuality, and current sexual norms. I will extend the notion of sexual accounts and

discourses, to the way in which they might represent particular *gendered* accounts or discourses or accounts or discourses that relate specifically to learning disability.

Like learning disability and sexuality, gender can be described as a social construction, and has been associated by feminists and within gender studies with the social characteristics attached to being a man or woman, or as Jackson (1999) puts it, the *differences* between men and women. As suggested earlier, feminine and masculine attributes such as women being passive or gentle, versus men being active and aggressive, that are often seen as ‘natural’ or innate, have thus been redefined in terms of constructions, and are described in terms of gender. Thus, as Bartky (1988:64) suggests, ‘We are born male and female, but not masculine or feminine. Femininity is an artifice, an achievement...’ Butler similarly argues that:

Gender is the repeated stylization of the body, a set of repeated acts within a highly rigid regulatory frame that congeal over time to produce the appearance of substance, of a natural sort of being. (1999:43-44)

Whilst an analytical decoupling of gender from sex is made possible by this, it has been argued (for example, by Butler, 1999 and Ramazanoğlu and Holland, 2000) for the need to maintain a sense of their connectedness in order to deconstruct the norms on which they are based.

Some, including Butler (1993) and Jackson (1999), have proposed that sex (as in being male or female) is also socially constructed (and is therefore not ‘essential’ or ‘biological’). However, whilst I recognise that this is an important point, in *this* study when I refer to gender, I refer to the assumed attributes that are attached to what are recognised to be, whether socially constructed or not, ‘man’ or ‘woman’. Thus, the gendered characteristics called ‘femininity’ are associated with women, and the gendered characteristics called ‘masculinity’ with men. These characteristics, being socially constructed, are not ‘fixed’. Thus: ‘Masculinity and femininity are defined not by biology but by social, cultural and psychological characteristics which are acquired through becoming a man or a woman in a particular society at a particular time’ (Jackson 1998:133). Gender has therefore been critiqued as a construction that brings

with its particular roles that, some argue, serve to subordinate women (Walby 1990, 1997, Richardson 1997, 2007).

In relation to the way in which gender is implicated in the ‘disciplining’ of particular categories of women, and drawing on work such as Foucault’s in relation to the way in which the ‘abnormal’ serves to regulate and define the norm, Butler (1999) argues that there is a strong incentive for men and women to ‘do’ gender on the basis that if it is not ‘done’ then ‘unintelligibility’ may follow. For example, a woman who does not ‘do’ gender, as in a stereotypical and normative femininity, is not ‘intelligible’ as a woman at all, and marks the boundaries of normal and abnormal.

Some working within disability studies have begun to explore what unintelligibility might mean for disabled people in relation to their categorisation as ‘disabled’, in the sense that disability marks the boundaries between normal/abnormal, or intelligible/unintelligible (Samuels 2002). Whilst this latter recognition is useful, I would also like to argue that women with learning disabilities might be seen as unintelligible at times both across and within gender and sexuality (in terms of being seen as being a woman, or being sexual), and that this is based on their categorisation as (unintelligible) people/women with learning disabilities. Clements *et al.* (1995) and Scior (2003) argue, for example, that services for people with learning disabilities are ‘gender blind’, with Clements *et al.* suggesting that both men and women with learning disabilities are ‘less than fully gendered’ (1995:1). Additionally, where gender and sexual identity overlap, Drake (1999) argues that the experience of disabled lesbians is one of marginality and exclusion on the basis of their invisibility, and quotes Ellis and Smith (1995:181), who say that: ‘disabled lesbians are marginalised, excluded and remain invisible to service providers, the disability movement and generally in society’ (Drake 1999:145).

There are a number of ways in which the unintelligibility of women with learning disabilities as gendered or sexual appears to be manifested. Motherhood and marriage, for example, are often still seen as problematic in relation to women who have learning disabilities. This has been seen in relation to eugenic policy in the early twentieth century, as outlined in Chapter One. However, there has been a persistence in such attitudes, with Oliver (1990:71) for example arguing that disabled women ‘...are



often denied access to traditional female roles because they are often seen as asexual and unsuitable for, or incapable of, motherhood.’ Kallianes and Rubenfeld also state that ‘what is expected, encouraged and, at times, compelled among non-disabled women is *not* expected, discouraged and proscribed among disabled women...’ (1997:204, original emphasis). Gillespie-Sells *et al.*’s (1998) empirical research with disabled women supports this view.

Tepper (2000:285) highlights the way in which sex is culturally constructed as ‘dangerous’ (although does not suggest disabled people might be seen as sexually dangerous), and that disabled people in particular are seen as ‘eternal children’<sup>32</sup>, and thus in need of protection from sex<sup>33</sup>:

...sex as a source of danger leads to the presumed need to protect us. Disabled populations are not viewed as acceptable candidates for reproduction or even capable of sex for pleasure. We are viewed as child-like and in need of protection.

As argued previously, people with learning disabilities, and disabled people generally, can be and/or are perceived to be, vulnerable (Craft 1983, Brown 1994, Sobsey 1994, Heyman and Huckle 1995). The sexual abuse of this group has been verified by empirical work in this area (McCarthy 1999, Peckham 2007, Peckham *et al.* 2007), which has compounded the sense that this group are vulnerable, a construction that frequently leads to their labelling as being childlike (Craft 1983, Heyman and Huckle 1995, Shakespeare *et al.* 1996, Tepper 2000), and in need of protection (Shakespeare *et al.* 1996, Tepper 2000).

On the basis of this, and the way in which this group have been constructed as innocent and asexual (although they have also been constructed as dangerous, this ‘dangerous’ sexuality has been constrained and regulated, and also seems to be less evident than during the eugenic period), I would suggest that any attempt by women with learning disabilities to ‘do’ what might be seen as adult femininity, or be seen as

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<sup>32</sup> Hockey and James (2003), Thomson (2004) and Renold (2005) all highlight the way in which childhood is equated with innocence and is seen to be inherently at odds with sexuality – it is an impossibility for the two to exist together (except in the form of abuse).

<sup>33</sup> Whilst Tepper sees the ‘missing discourse of pleasure’ she discusses as gendered, she does not discuss this further in relation to disabled women, however.

sexual, is less likely to be recognised than might be the case for other women<sup>34</sup>. The differential access to particular norms has been highlighted by Brown, who argues:

...the sense of self which we label “sexuality” varies according to social position, resources and ideology...as a goal to be aspired towards it is more accurately perceived as a property which is largely ascribed, a currency through which social status and group membership is conferred and regulated (1994:133).

Nevertheless, as argued earlier, this does not necessarily mean that women with learning disabilities will be free from the disciplining effects of particular gendered or sexual roles, just because these roles are less achievable. Williams and Nind (1999) imply that such effects are in place, when they argue that the service principle of normalisation actively disadvantages women who have learning disabilities by encouraging them to become part of a ‘club’ that excludes them. Whilst some see services (Clements *et al.* 1995, Scior 2003) and the service principle of normalisation (Williams and Nind 1999) as ‘gender blind’, others argue that they are unquestionably disciplining women with learning disabilities into normative roles. Brown and Smith (1992), for example, assert that services fail to question the negative aspects of gender roles for women, whilst disciplining women with learning disabilities *into* these roles. (They suggest for example that women in mixed residential service settings are, because of this, unquestioningly encouraged to take part in normative household roles similar to those of wives, such as cleaning and cooking.) This suggests that such women receive conflicting messages in relation to gendered roles, and that they are, at least in some, perhaps limited ways, perceived as ‘women’.

Morris (1993b:88) has usefully argued that it is not simply a case that disabled women are *denied* stereotypical (though heterosexual) female roles, and/or they are disciplined *into* them, saying:

Disabled women...receive conflicting messages from the non-disabled society: they are considered to be unable to fulfil the role of homemaker, wife and mother, neither can they conform to the stereotype of femininity as it applies to

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<sup>34</sup> This is not to say that all non-disabled women have equal access to femininity/sexuality, or that all non-disabled women have more access to femininity/sexuality than disabled women. Skeggs (2001) for example highlights the way in which class affects access to these identities.

physical appearance; yet at the same time, the passivity and dependency which lies at the heart of disability as a social construct is certainly compatible with what it means to be a woman in our society.

Similarly, Oliver (1990:72) asserts that 'there are strong links between the assumed passivity of disabled people and the assumed passivity of women.' Lonsdale's (1990) research with disabled women suggests that respondents were constituted as both passive and dependent. Morris hints at the unintelligibility of disabled women in some roles, for example wife and mother, but not in others, such as being passive and dependent. This suggests then, a still more complex picture, that takes us beyond the idea that all gendered roles are 'off-limits' to disabled women, or they will be disciplined into an approximation of them. In the data chapters I will explore some of these complexities, particularly in relation to what appear to be 'traditional' normative roles in relation to marriage and having children.

Whilst stereotypical sexual and gendered roles have been critiqued extensively by feminists (for example, Hollway 1984, Bartky 1988, Walby 1990, Lees 1993, 1997, Jackson 1996b, Jackson 1997, Richardson 1997, Jackson 2007), Skeggs (1997, 2001), in her work on class, highlights the way in which such roles might work 'positively' for some women when she suggests that femininity is one of the few forms of cultural capital available to working class women. From another viewpoint, Giddens has said that 'on the one hand romantic love has helped keep women "in their place" – home', and on the other, that it 'can be seen as an active, and radical engagement with the "maleness" of modern society' (1992:2). Thus, whilst these roles limit the ways in which women can be, they might also act to 'open up' possibilities by giving particular women a cultural capital that they would not have, if they refused to 'do' gender. This is not just about being intelligible or not, it is about the additional capital that is associated with that intelligibility.

In relation to the feminine role of mother, Kallianes and Rubenfeld (1997:205) have thus stated that

It may seem a paradox that issues for which feminists have struggled – for women not to be defined sexually, for the right to roles other than mothers – appear the opposite of what disabled women demand...However, rather than

differing perspectives, they are, in fact, two sides of the same coin...if all women have the right to choose to bear a child, then all women must also have the right to bear children.

Both Scior's (2003) research and Barron's (1997) Swedish research based on interviews with six young disabled women, suggest that being perceived as a 'woman' is important to some disabled women, and that performing 'traditional' feminine roles are integral to this. Barron (1997:223) has suggested that this 'can be understood as a means of counterbalancing an early acquired role of passive recipient', a suggestion that I will return to in Chapter Six, and which challenges the notion that the perceived passivity of women and disabled people might work together 'negatively' for disabled women.

Finally, as Shildrick (1997:47) suggests, specifically in relation to gender, the body is '...also crossed and mediated by quasi-structural, but in reality equally discursive, categories, such as class, ethnicity, (dis)ability and sexual preference.' Butler (1993:115) similarly describes identities in terms of 'a dynamic map of power in which identities are constituted and/or erased, deployed and/or paralyzed.' Whilst I would argue that this is true, it is also true that some identities 'stick' more than others. As Shildrick (1997:13) asserts: 'The point is that for all their fluidity, not all discourses are of equal status...' Thus, despite the force of gendered discourses, learning disability might be a stronger influence on women with learning disabilities' experiences than gender or other identities. Block (2000:240) has argued that

Disability, when applied as medical or psychological diagnoses, takes the culturally, socially, and historically derived identity of an individual and subsumes it beneath a designation of pathology. When an individual enters the biomedical and psychosocial service-systems as disabled every other personal characteristic becomes secondary; the person becomes defined by their disability.

Davies and Jenkins (1997:95) have argued that learning disability forms a 'master status' – also described by Baron *et al.* as a 'master category' (1999:492) or 'master identity (1999:493), that dominates all other social identities in terms of the way in which people with learning disabilities are perceived. For example, in terms of the transition from child to adult, Baron *et al.* (1999) suggest that because of the structural power of the category of learning disability, people so labelled often fail to move from

child to adult status; they become ‘stuck’ – and transitional markers of adulthood, such as marriage and childbirth are less likely to be achieved. The people they case-studied (two men and one woman with learning disabilities from the UK, at different stages of the life course) were, the researchers argued, ‘held tightly by the discourses of law, social work, education and the family, which impose the identity “learning difficulties” prohibiting them from negotiating risk and developing more autonomous identities’ (1999:497).

This analysis however, threatens to obscure the effects of gender differences. It was clear, for example, within my review of the literature, as outlined in Chapter One, that empirical research on men tended to focus on the ‘dangerous’ nature of their relationship with sexuality. The little research done on women, tended to focus on their vulnerability to sexual abuse. Thus, whilst both groups have, and are, positioned as both vulnerable and dangerous, there is nevertheless a tendency for them to be perceived and constructed differently. The way in which women are perceived, and perceive themselves in relation to sexuality, will be a focus within my own analysis, and is explored particularly in Chapter Six. I would suggest therefore, that whilst learning disability might form a master status, gender necessarily impacts upon the way in which people with learning disabilities are perceived and disciplined in relation to sexuality, as it does with all of us (Gagnon and Simon 1974).

## **Conclusion: Situating the Research**

This research is concerned with the ways in which research respondents give meaning to sexuality. These meanings are developed through respondents’ everyday interaction with, in particular, significant others (such as family and service professionals), and the multiple accounts of sexuality that respondents thus encounter. These accounts are embedded within, and underscore, wider discourses. Institutional practices likewise reflect and underscore accounts and discourses. The meanings associated with sexuality are therefore informed by, and represent, the many ways in which the norms associated with gender, sexuality and learning disability might intersect.

The norms associated with these socially constructed accounts and discourses (as well as practices) are informed, and intersect, with the ways in which gender and learning disability are defined and categorised. Women with learning disabilities are sexed (they are women), and have been labelled as having a learning disability. Yet it seems that this group are in many ways denied particular aspects associated with 'womanhood' (for example to have children), as well as a 'normal' sexuality. This I have argued is because of their relative 'unintelligibility' in these roles, and in certain contexts, on the basis of their 'learning disability' categorisation. Nevertheless, they might also be 'disciplined' into particular gendered and sexual roles, or an approximation of them. However, access to such norms, however restrictive, and perhaps, illusory, have the potential to offer women with learning disabilities an opportunity to 'do' normal, and thus these might seem a valued 'choice' for them, despite their regulatory nature.

As highlighted, little research has been conducted in relation to people with learning disabilities and sexuality, and none specifically looking at the institutional effects of family and professionals in relation to how women with learning disabilities ascribe meaning to this aspect of their lives. Thus this research asks the question 'what institutional accounts of sexuality, and what institutional practices that might underscore or challenge these accounts, do respondents come into contact with?', and 'how do respondents themselves give meaning to sexuality within institutional contexts?'

Although this study focuses on a small group of women, the findings resulting from it should be of interest to policy-makers and practitioners, on the basis that it gives insight into the way in which some women with learning disabilities experience their lives and the services they use. More specifically, the findings represent a first step in understanding how this group have developed a sense of what sexuality is, how it applies to them, and how this negotiation relates to the development of their sense of sexuality or sense of sexual self. Without this sense of sexual self, it is unlikely that this group will also see themselves as sexual agents, or claim the sexual rights that Government policy acknowledges to be theirs.

On a final note to the chapter, I would like to highlight the way in which the concepts I am using are to some extent simplified. Whilst I have described a

normal/abnormal binary for example, this is, however, a construction. Nevertheless, in order to theorise the ways in which disability, learning disability and gender might operate, this binary is discussed because it exists both conceptually and socially. Further, although there might be a (constructed) border between abnormal/normal, this border might not be clearly defined: as Rubin (1993) suggests, normality/abnormality is perhaps better represented in terms of a hierarchy. In addition, it is also possible that women with learning disabilities might not be fully denied access to 'womanhood' or a sexuality; access is likely to be contextual and contingent. Thus it is unlikely that respondents will all experience regulation or norms in the same way, as will be shown in later discussion.

It is also interesting to note that Butler (1999) argues that the 'doing' of gender and sexuality, and the acquisition of intelligibility, is impossible for all of us. Nevertheless, it is clear that some people are more intelligible than others: those who most conform to 'able', gendered and (hetero)sexual norms; and that people are 'read' as intelligible or not. As Galvin (2006:503) has noted:

The winners in this process of normalisation are supposedly those who can most closely approximate these qualities [associated with the norm] and among the losers are those who remain passive, dependent, poor and/or unattractive by normative standards.

Additionally, whilst I focus on learning disability and gender here, I do not necessarily take into full account the multiplicity of identity intersections that influence people's lives. Butler (1993) has described the virtual impossibility of examining this process. It is with this in mind that I suggest that whilst my own analysis of learning disability, sexuality and gender might thus represent an oversimplification, and will also obscure the effects of other social factors, that there is still a benefit to this in that it might provide a greater understanding of how sexuality/gender/learning disability work together.

Further, this discussion of regulation, disciplining, and normative forces implies that individual agency might not exist. This is of course unlikely to be the case. Taking Foucault's conceptualisation of power, all people, marginalised groups included, have agency because power is not possessed by one 'dominant force' (1991). It is not

something that can be fixed or 'held' (1991) it is 'multiple and mobile' (1990:98). Power is more of a process or strategy that is expressed, and 'cannot be localised in a particular type of institution or state apparatus' (1991:26). Nevertheless, such agency is restricted by its necessary location within a field of normative discourses, as Foucault suggests, 'the soul (as in the disciplined subject) is the effect and instrument of a political anatomy; the soul is the prison of the body' (1975:30). Whilst Soper (1993) has described this form of agency as nihilistic, and Ramazanoğlu and Holland argue that the notion that subjects might have agency 'has no place in most of Foucault's thought' (1993:240), this conceptualisation of agency within disciplinary frameworks is useful in that it describes how individuals are located within shifting and multiple networks of power, in which shifting and multiple meanings are negotiated, as are the women in this study.

Ultimately, as Hollway (1984) argues, we position ourselves within, and make meaning from, the range of discourses that are available to us. Whilst Jackson (1996b, 1999) questions how, within such frameworks, we position ourselves as sexed and gendered, Henriques *et al.* posit that this is done via investment in, or an 'emotional commitment' with (1984:205), particular subject positions. Such investments are entangled with psychological processes whereby discursive practices are implicated with the construction of desire (Henriques *et al.* 1984) and our personal history (Hollway 1984). Thus, what we take to be 'who we are' and what we want from life as a unique individual is in fact constructed through discourse. Power is also implicated since, as Hollway (1984) suggests, particular positions offer more power than others: for example, she says that for women 'there is a status and power attached to being attractive to men' (1984:233), despite the way in which such gendered practices might contribute to the subordination of women. She also argues that such positioning feels 'gender-appropriate' (1984:241); what Butler (1999) would describe as 'doing' gender.

Nevertheless, investments are made within a field of competing discourses, and such decisions are never straightforward. Contemporary discourses that suggest that women have more sexual choice than previously clash with discourses that frame them negatively for acting as sexual agents (Lees 1993, 1997). Thus, whilst women might invest in particular subject positions that make them more powerful, they are,



nevertheless, also likely to be positioned negatively for doing so. Further, whilst various subject positions are available, and various investments can therefore be made, these are made in different contexts which operate with different 'rules'. In addition, some discourses are more powerful than others: women are still more likely to be labelled 'sluts' than 'sexual agents' when they have multiple sexual partners or have 'one night stands'. Thus, whilst we are apparently free to make investments in a range of subject positions, there are costs in taking them up.

Finally, critics of the social model have highlighted the way in which impairment is sidelined by the way in which it separates impairment from disability (French 1993, Crow 1996, Shakespeare and Watson 1997, Corker and French 1999, Thomas 1999, Tremain 2002). However, for the purposes of this study I focus, in the main, on the socially constructed nature of 'learning disability' and assumptions that have become associated with that label, rather than the effects of impairment. This is not to suggest that impairment does not have effects.

Having described the theoretical underpinnings to this thesis, the following chapter will focus on the research methodology.

## CHAPTER THREE

### Methodology

#### Introduction

Here I will outline the methodology used and the methodological issues encountered therein when conducting this research. I will begin by briefly outlining my epistemological framework. I will then describe the initial research design, which subsequently changed. I will go on to look more closely at the methods used: focus group, interview and participant observation. I will conclude by discussing some of the ethical issues encountered whilst doing the research.

#### Epistemological Framework

This research focuses on the way in which women with learning disabilities make meaning of sexuality, and how institutional processes might influence this. It takes a broadly qualitative approach informed by feminist and disability studies. Feminist and disability studies point to the need for understanding the lives of marginalised groups; in particular, women (Smith 1988, Stanley and Wise 1993) and disabled people (Abberley 1989, Shakespeare *et al.* 1996, Goodley 1998, Young and Quibell 2000). Such groups, they argue, are under-represented in society. Further, such under-representation means that our understandings of the world are necessarily skewed: the knowledge we have of it is both shaped by, and from, the viewpoint of white, middle-class, non-disabled men.

Some working in these disciplines have further suggested that neither women (Lorde 1984, Harding 1987, Harding 1991) nor disabled people (Morris 1991, Shakespeare *et al.* 1996, Goodley 1998) form monolithic groups. Each includes people of different classes, races, ethnicities, dis/abilities and so on, and each of these intersections bring with them different experiences. As already suggested, disability studies has been criticised for ignoring the specific experiences of disabled women (McCarthy 1999, Traustadóttir and Johnson 2000) and people with learning disabilities (McCarthy 1999, Goodley 2001), and feminist work has been criticised for ignoring the

experiences of disabled women (Morris 1991, Begum 1992). Thus, such groups' experiences have remained relatively invisible despite the emergence of greater understandings of both women's (Lorde 1984, Harding 1991) and disabled people's lives. This research explores the lives and thoughts, therefore, of a group that lies at the intersection of disability and gender, and disability and learning disability: women with learning disabilities. In doing so it aims to produce new knowledges about this under-represented group.

The study uses semi-structured interview and focus group techniques in part because of the way in which they allow for the in-depth exploration of people's lives, and the way in which they allow relatively unmediated access to women's voices and experiences (Reinharz 1992, Thomas 1999). These 'voices', I argue, have the potential to challenge what we think we 'know' about this group in relation to sexuality, in the form of 'sexual stories' (Plummer 1995). As Plummer asserts:

At the broadest level, stories have an important task to perform in the wider culture. Most self-evidently, sexual stories provide information, even education, in the service of reform and change. They can work a quiet 'catharsis of comprehension'. (1995:175)

Some, particularly within disability studies<sup>35</sup>, have argued against focusing on people's lives on the basis that this individualises disabled people and ignores the wider social structures that oppress them (Finkelstein 1980, Oliver 1990, Oliver and Barnes 1998). However, such criticisms fail to acknowledge the way in which individuals' lives, and the interaction that they have with others, are enmeshed in, and constitutive of, wider social relations (Smith 1988, Stanley and Wise 1993). Thus, whilst this study attempts to draw out the voices of women with learning disabilities, these voices also usefully reflect the contexts within which they are embedded.

The research also draws on the idea of 'local knowledges' (Josselson and Lieblich 1995), the 'reality' of the respondent (Lloyd *et al.* 2006) and of 'narrative truth' (Plummer 1995). It is the way in which respondents perceive their social worlds that I see as important, as it is these perceptions that act to influence how they live their sexual

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<sup>35</sup> There appears to be a split in thinking within the discipline on this matter, with some arguing for a focus on the disabled 'expert', and others on the structures that disable them.

lives<sup>36</sup>. These stories are also produced in *shifting* contexts. As Gergen (2004) suggests, stories are not stable, nor are they the only ones to be told. This research therefore recognises that the voices telling these stories might tell different accounts in different contexts.

However, whilst this study aims to present the voices or local knowledges of women with learning disabilities, it also seeks to engage with these voices, to interpret them, and to make sense of them as both *individual* voices and as voices that represent a marginalised *group* that exists within, and forms a part of, a wider network of social relations. In relation to this process of interpretation, Plummer (1995) argues that research stories are necessarily produced by researcher *and* participant, *as well as* reader. These stories (or voices) are interpreted firstly by myself, which involves what Atkinson (1992:26) describes as ‘textual conversion’, and interpreted again by others when they bring their own opinions and experiences to bear on their ‘reading’ of them. Thus, whilst some within disability studies (Goodley 1996, Brigham 1998, Stalker 1998) suggest that the disabled voice can become ‘subsumed within the “academic voice” which abstracts, generalises and explains’ (Brigham 1998:149), I would suggest that the separation between voice, and the analysis and interpretation of that voice (Humphries and Martin 2000), is difficult, and likely to be impossible. In addition, such interpretation can bring an additional light to bear on respondents’ stories through the contextualisation and theorisation of them. Nevertheless, my desire to represent voice within my wider interpretation of it is an aspect of the research with which I have struggled, as reflected in later discussion.

Finally, the research was designed to allow some degree of autonomy to its participants in order to try and ‘equalise’ the relationship between myself and them. For example, the use of semi-structured interviews and an initial focus group were also, in part, to give participants a degree of control over what aspects of sexuality were researched and the kind of data that was gathered (Reinharz 1992, Kitzinger and Barbour 1999, Hyams 2004). Semi-structured interviews allow respondents more ‘room’ to direct discussion, and Wilkinson (1999) suggests that focus groups can shift power

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<sup>36</sup> For example, if a participant *perceives* that a member of their family has denied them the opportunity to have a sexual relationship, whether or not the family member has *actually* done so is relatively irrelevant if this perception influences the participant’s actions and opinions.

towards participants due to the focus on their interaction rather than the interaction between researcher and respondent. However, it is also recognised that power is not necessarily 'equalised' by such approaches, and that this particular research was driven by my own research interests and, as suggested, open to my own interpretation of the data. Nevertheless, the research takes as its starting point the lives and thoughts of respondents (Smith 1988, Harding 1987, Harding 1991), and a commitment towards articulating these in a way that generates what Stanley (2003) calls 'accountable knowledge', rather than simply data (Finch 1993, Stanley and Wise 1993, Shakespeare 1996).

## Research Design

All participants were to be drawn from a women's group that met monthly<sup>37</sup>. The purpose of researching with a small group of women in depth was based on the desire to explore the complexity of individual experience. My initial research design included one or more initial focus groups, two 'waves' of interviews with at least twenty women, and a final focus group. It also included the possibility of interviewing key informant professionals when my original focus, specifically upon formal services, was still in place (a focus I later abandoned).

The first focus group was to serve as an initial exploration of the sexual issues influencing respondents' lives, an established method to map themes in under-researched areas (Frey and Montana 1993, Kitzinger 1994, Kitzinger and Barbour 1999), and to provide a starting-point and context for the interviews (Morgan 1997). As Mitchell (1999) highlights, whilst focus groups give access to more 'public' knowledge(s)<sup>38</sup>, interviews give access to individual knowledge(s).

The focus group was also intended to help me to learn more about the culture and language of the group I would be doing research with (Deutscher 1984, Kitzinger 1994, Kitzinger and Barbour 1999, Fielding and Thomas 2001), particularly in relation to their

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<sup>37</sup> I have not included pen portraits of participants on the basis that they form a small, recognisable community.

<sup>38</sup> I use the term 'knowledge(s)' to refer to the way in which what are perceived to be 'truths' can be understood in many (sometimes conflicting) ways, i.e. there is no one 'truth' about sexuality. Whilst knowledge(s) are not discourses, they reflect, reinforce and exist within these.

understanding of sexuality. I was particularly aware of the cultural differences between myself and the participants. These differences included home background (most lived in residential services, others in impoverished areas, most were from the region in which the research took place – I was not), and level of education.

By observing the way in which focus group participants referred to sexuality, I could then use the same (hopefully familiar) terminology that they (and perhaps other respondents) would use in the following interviews. As Schwartzman (1993:59) suggests, 'Responses that build on terms, expressions, or experiences used by the informant are much more likely to produce richer informant responses to questions.'

The second wave of interviews were to be based on an initial analysis of the first, and were to help clarify and probe more deeply into the first wave findings, as well as take into account new emerging themes (Lee 1993). The final focus group was to ideally include the original group, and was to serve as an opportunity to look at the themes that had emerged from the data, and to receive feedback on both these, and my interpretation of them (Humphries and Martin 2000).

Here I will discuss the process of 'working through' this research design, and the ways in which it changed over time.

## **Sampling**

As suggested, respondents were accessed via an existing women's group. The organisation where the women met<sup>39</sup> aimed to develop advocacy services and self-advocacy skills for disabled people. It was run by a team of paid staff and by a larger group of mainly disabled volunteers. The women's group was facilitated by a (non-disabled) paid member of staff, subsequently described as the 'group facilitator'. The group had members who volunteered at the centre, and members who had experience of participating in research<sup>40</sup>.

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<sup>39</sup> I have not used the organisation's name in order to help maintain participants' anonymity.

<sup>40</sup> This included helping run courses at the centre (both for disabled and non-disabled people), as well as visiting schools, social workers and medical practitioners to talk about being disabled. The organisation where the women's group met also conducts research on the behalf of government agencies, and gives access to university students conducting research.

Lennox *et al.* (2005) highlight the difficulties in accessing people with learning disabilities to do research. Access to participants as an existing group was anticipated to be easier than trying to access individuals<sup>41</sup>, particularly given my limited resources as a research student. Encountering ‘gatekeepers’ to people with learning disabilities is common (Stalker 1998, Lennox *et al.* 2005) as this group are often seen as vulnerable. Although the women’s group facilitator and the organisation where the women met acted as gatekeepers to the group, they believed that service users were able to make their own decisions<sup>42</sup>. This meant that although I needed permission – and support – to access the group, once this was granted individuals were free to decide on their level of involvement.

Discussing ‘sensitive’ issues in research might be considered difficult (Lennox *et al.* 2005). One benefit of targeting a group was the potential for support for participants from *within* the group that would not be available to them if taking part in a focus group with strangers, or being interviewed without knowing other interviewees. As became apparent during the informal time I spent with them, many were emotionally close to one another. Additionally, some members of the group already had experience of research interviews and of talking about themselves with others through telling life stories<sup>43</sup>. This suggested that such respondents might find it easier than those who had not been involved in such work to discuss the ‘sensitive’ area of sexuality. On the other hand, those individuals with research experience might then have had assumptions about what *my* research might be about and what might be expected of them<sup>44</sup>. Additionally, those used to telling life stories might re-iterate a rehearsed story with me (Fielding and Thomas 2001) rather than focus on my question. It is also notable that the women’s group had discussed sexuality before as a group, although in practice, given my own observations, this would probably have involved only a handful of members in direct conversation.

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<sup>41</sup> This would probably have involved approaching agencies that provide services to people across a range of locations, which would involve dealing with multiple gatekeepers.

<sup>42</sup> For example, the facilitator suggested not sending a research information sheet to one participant’s parents (with whom she lived), on the basis that they would be likely to try and stop the participant from being involved, despite her own wishes.

<sup>43</sup> The number of women who had had this experience was not made clear, although it is likely, given the details respondents gave me about how they spent their time that this was limited to less than five.

<sup>44</sup> This did not seem to be a problem in practice.

The wider women's group, as suggested, consisted of a 'core' group who had known each other for a long time, and a number of others who attended occasionally. Attendance also varied from month to month. This meant that sometimes attendees would agree to consider becoming a participant, but would not be in the group again until months later (or not at all in some cases). Whilst this had what might be seen as negative impacts on the recruitment and interview process, this fluctuation also brought in new attendees that I could then approach.

All of the respondents were white. This was not a deliberate choice: none of the users I met through the organisation were from other racial groups. With respect to class, this was not considered in terms of sampling. This was partly because I did not feel comfortable in ascribing a class to respondents, or asking them to. This was due, in part, to my awareness of my own background, which might be considered privileged in comparison with the women in the group. This is not to suggest that class did not have effects. As Skeggs (1997, 2001) has argued, class is a significant influence on the sexuality of women. The lack of focus on class in this research therefore has the potential to obscure its effects<sup>45</sup>. Most women's narratives showed a strongly heterosexual discourse – whether or not they had experienced heterosexual relationships or the norms of heterosexual marriage and parenthood. None of the women identified themselves as being a lesbian or talked about being attracted to other women, and many described same-sex relationships in negative terms. For the purposes of this research I have thus categorised respondents as heterosexual. However, this does not mean that I think that the construction of sexual identity is necessarily straightforward.

## **Access**

Initial contact with the women's group was through someone who I had met both professionally and on a casual basis through a work colleague, and who worked at the organisation where the women met. (In a professional role, I had also supported clients with learning disabilities who worked and attended courses at the same organisation.)

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<sup>45</sup> I did, however, ask many respondents about whether or not they had enough money to socialise (given that one indicator of class is economic income). None suggested that their incomes were insufficient, although few were employed.



This contact was able to act as an initial ‘go-between’ between myself and the group facilitator, with whom I communicated via letter (see Appendix One) and email, before arranging to meet. As Lennox *et al.* (2005) highlight, targeting potential ‘allies’ in an organisation can help to ease access, as well as being useful in managing the subsequent research relationship with the organisation. It has also been suggested that gaining access via management can make others within that organisation ‘suspicious’ of your role (May 2001, Lennox *et al.* 2005). This suggests that my introduction to the organisation, via a colleague of the facilitator rather than the facilitator’s manager, might have made access into the women’s group and my subsequent relationship with the facilitator more ‘comfortable’.

At our first meeting the facilitator and myself discussed the possibility of women’s group members working on the research in a participatory role, in line with my aims to conduct as emancipatory a piece of research as possible. After discussion with my supervisors, who highlighted the need for the research to be fully mine (and not co-authored), I suggested to the facilitator a compromise whereby members of the women’s group could act as advisors rather than participants. In response, the facilitator suggested that I only interview respondents on the basis that heavier involvement might confuse respondents, some of whom had taken a more active role in research before. The facilitator made it clear that although the women themselves had the right to say whether or not they wished to participate, she felt that she also had a role in ‘protecting’ them. After discussion, and after my initial presentation of the research to the group, my attendance at the women’s monthly meetings was however agreed, in addition to conducting interviews. Permission was also given by the organisation’s chief executive.

Contact with the group itself occurred six months after this first meeting with the facilitator, in March 2004. I gave a thirty minute presentation and invited an initial response. Of the ten women who were there, eight consented to be interviewed and five agreed to attend a focus group (a first informal step in the consent procedure, outlined below)<sup>46</sup>. The direct involvement of the group facilitator is likely to have increased the

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<sup>46</sup> It is important to note that whilst I offered to talk to respondents’ families or support workers about the research, I did not seek family/support worker consent to do research as I felt that this would undermine respondents’ own right to consent. I did produce an information sheet (Appendix Four) and a letter

number of responses (Lennox *et al.* 2005) on the basis that she, someone that respondents knew, was ‘validating’ the research. I gave each woman a leaflet to take away (Appendix Three) and encouraged them to discuss the research with friends and/or family if they wished<sup>47</sup>. The facilitator sent the remaining group members (the women’s group membership totalled around twenty-four at that time) a letter outlining the research. One positive response emerged from this, to attend the focus group. The subsequent low level of response was perhaps explained by the group facilitator’s suggestion that verbal communication worked more effectively with this group. It might also be argued that the women were less likely to agree to be involved in research with someone they had never met. It was decided that one focus group would take place with six participants prior to the interviews. This focus group took place in June 2004.

Additional interviewees were recruited during the women’s group’s monthly meetings that I began attending in December 2004. This involved talking to each person aside from the group where possible, explaining what the research was about, giving them the information sheet on the research, and explaining some of the rights they would have if they agreed to take part. This subsequent group of participants were to some extent ‘hand-picked’, in order to involve women who I felt might understand the research and be able to communicate their experiences. This meant that I excluded a number of women on the basis that they had more severe impairments. I was not comfortable with this ethically since I had wanted my research to be both inclusive<sup>48</sup> and representative. However, I did not feel that I could deal with the extra difficulties (including difficulties with consent and the possible involvement of support workers<sup>49</sup>) that this would have posed. As a result, the findings of the research represent the views

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explaining the research (Appendix Seven) for parents/support workers, but few participants chose to pass these on.

<sup>47</sup> I was aware that friends and family might influence respondents positively (encourage them) or negatively (discourage them) in relation to their participation in the research, and that this might be contrary to respondents’ own wishes. Nevertheless, I felt that it was important that respondents discussed the research with people that they trusted, if they so wished, so that they understood as fully as possible what the research might entail. (I recognise, however, that approaching family and friends might be difficult, given the research topic.)

<sup>48</sup> As Lloyd *et al.* (2006) argue, there is a need to include those with expressive language deficits, as well as those with severe impairments.

<sup>49</sup> Owens (2007:304) has highlighted the overlapping and conflicting roles (for example gatekeeper, decision-maker, proxy, advocate, carer and so on) that staff might experience as ‘interpreters and proxies’ for people with learning disabilities. Lloyd *et al.* (2006) also argue that in using carers as proxies we learn more about the carers’ concerns than we do about those they support.

of a *particular* group of women, who might not be representative of women with learning disabilities in general. This said, I continue to believe that it is important to consider ways in which people with more severe impairments can be involved in research (Owens 2007).

Recruitment was steady, but slow. At one point the possibility of recruiting respondents outside of the group was discussed with my research supervisors as well as the group facilitator. The facilitator suggested that I spend time in the centre ‘drop-in’ (a place where people with learning disabilities could meet informally), approaching the women there. I felt awkward about this (it felt particularly predatory!)<sup>50</sup>, but did spend time there during breaks or after the monthly women’s group meetings, and before meeting with interview participants. None of the women approached in the drop-in agreed to be involved, reinforcing the notion that my direct involvement in an existing group, and the direct support and involvement of the facilitator, increased my chances of recruitment, as well as reflecting the effects of recruiting in a mixed-sex environment. Interviews began in February 2005 and were completed in November 2005. Second interviews overlapped with the first and ran from August 2005 to November 2005. In all, six women participated in the focus group, and sixteen women participated in the interviews with a further eight taking part in second interviews. Despite initial plans to interview all respondents twice, it was decided to do so only where additional or more in-depth information might prove useful. Additionally, some respondents had stopped attending the group and were not available.

Throughout the research there was a sense that because I attended the women’s group, some women connected me with the organisation, regardless of my assertions that I was not. As Schwartzman (1993:48) suggests: ‘No matter what role one tries to adopt in a fieldwork situation...informants will make sense of the researcher in the way that they make sense of all other strangers who appear and begin to ask questions.’ Having worked with people who have learning disabilities and having supported some of them on courses at this organisation, it was relatively easy to slip into a pseudo-staff

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<sup>50</sup> This awkwardness was probably due to my own lack of confidence at this stage at approaching people I did not know. Confidence grew over time in this regard, and I found that no one seemed offended by my approaching them. It is important to note that when I did approach people, I ensured that when I talked about the research I did so in relative privacy (e.g. asking people whether they minded coming out of the room to a quiet space so I could talk to them).

or support worker role, and at times I had to remind myself of my role as researcher. However, professional experience might also have been beneficial, particularly whilst observing the *Sex, Love and Relationships* course. May (2001:162) describes something called ‘social consensus’, which is achieved through a researcher having knowledge of a particular social setting and the rules that govern it, which increases the possibility of the researcher also ‘understanding’ that setting and the interactions within it. Having worked in similar settings, I already knew some of the ‘rules of the game’.

My attendance at the group, and my acceptance within it, also appeared to make recruitment easier. Further, it gave me a sense of how the group interacted, and helped me to develop rapport with members (Lloyd *et al.* 2006), which seemed to make interviewing a more relaxed process, a particularly important factor considering the subject matter. Sin (2005) however highlights the way in which such rapport can also be used to gain more information than might otherwise be obtained; that it can be used ‘cynically’ (Homan 1991). Finch (1993:169) also highlights the way in which the researcher-respondent dynamic, when involving two women, is a ‘special situation’, arguing that this situation makes it ‘easy to get women to talk’<sup>51</sup>. This too can result in the exploitation of respondents. Whilst I was obviously not wishing to do this, I was, nevertheless aware of how my being a woman would affect the research. Finch also argues that the isolation that some women experience influences their openness, and I felt that on more than one occasion respondents who lacked opportunities to be with others (as shown in the data), welcomed the opportunity to talk.

Towards the end of the fieldwork the women’s group facilitator left the organisation. Although this might have caused problems in relation to the research, particularly in relation to my continued access, I was on familiar terms with the women themselves by this time and was no longer as reliant on the facilitator for help. When a new facilitator<sup>52</sup> was found for the group I found her particularly supportive, and she

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<sup>51</sup> Humphries and Martin (2000) suggest that this can obscure the difference in status between researcher and researched.

<sup>52</sup> Unless stated otherwise, when referring to ‘the facilitator’ I am referring to the original facilitator.

gave me the opportunity to feed back to the women's group some of my initial findings, and to discuss sexuality with them more generally<sup>53</sup>.

During the fieldwork, and encouraged by my research supervisors, I decided to conduct participant observation during a course on sexuality held at the centre. The purpose of this was to contextualise data gained from focus group participants and interviewees, over half of whom had attended this course, with many referring to it<sup>54</sup>. Access to conduct the participant observation on this course (the *Sex, Love and Relationships* course<sup>55</sup>) was negotiated via the women's group facilitator, who approached the main course facilitator on my behalf. I provided them with an information sheet about the research (Appendix Ten), and my thoughts on where the observation would fit into that). I also completed a statement of what I would do during the observation – what information I wanted to get and what kinds of notes I would take. The women's group facilitator (who had facilitated on this course herself) suggested that access would be given on the basis that no names were used, and that my data was restricted to course content and the kind of generalised comments made by course members that might be included in a course report. Access was also granted on the basis that I would work alongside facilitators as if I were a volunteer. This mainly involved helping out at lunchtime (distributing food and washing up). I felt more comfortable in this role than I would have done remaining outside of the group (explicitly, and rather obviously, observing). However, this did mean that writing fieldwork notes was restricted to the occasional note made during the session<sup>56</sup>, with fuller notes added before the journey home, followed up with yet fuller typewritten notes as soon as possible after that (usually completed before the next session). The first course that might have been available for me to observe was with a group of students from a local college, which was to have taken place over five consecutive days. Access to this course was denied on the basis that this was a group of people aged under eighteen. A second

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<sup>53</sup> I have chosen not to use this discussion as data on the basis that formal consent was not given to use it (although informal verbal consent was), and because despite their comments supporting some of those made by respondents (comments were made by women who had not been respondents as well as by those who had been) there was little to add to the data I already had.

<sup>54</sup> Those attending spanned an age range of twenty-nine to seventy-eight.

<sup>55</sup> A pseudonym.

<sup>56</sup> As well as jottings, I devised a chart (Lee 2000) to try and map out participants' comments in relation to the time of day, in case this affected their responses (what might be taken for boredom might simply be tiredness for example).

course in the year was run, this time by, and for, the organisation (i.e. not a contracted-out course on the behalf of anybody else), and access to observe on this course was granted.

## **Focus Groups**

### *Planning*

Although I had planned to conduct one or more focus groups at the beginning of the research, and one or more at the end, only one focus group took place, at the beginning. This focus group was not followed up with others due to the limited numbers of women wishing to be involved, and the final focus group was not conducted because the data collected via interviews proved to be very personal as well as nuanced, and a group discussion of sometimes painful subject matter, that was difficult to fit into neat discussion points, seemed inappropriate<sup>57</sup>. Women due to attend the initial focus group wanted it to take place at the centre. This appeared to be a ‘comfortable’ location for them, and nobody seemed to feel that it would constrain what they could talk about. The meeting was planned to occur in the afternoon of one of their usual sessions. The women would therefore already be on the premises and hopefully be more likely to attend. Travel costs<sup>58</sup> would also be minimised.

The room was chosen by the group facilitator, but was also the best one for conducting the focus group – an appropriate size with accessible plugs, tables, and a flip chart (Kitzinger and Barbour 1999). The main aim was to create the safe and friendly atmosphere advocated by Atkinson (1993) whilst addressing the practicalities of running and recording the session. I visited a week in advance to view the room and finalise arrangements. On the day, chairs were arranged in a circle and participants sat where they felt comfortable. I audio taped the group, took notes and used a flipchart to record the main points discussed. The session lasted one-and-a-half hours. Drinks and cakes were available.

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<sup>57</sup> Although I did take the opportunity of seeking some very general feedback in a session on sexuality, as described earlier.

<sup>58</sup> I offered to pay for participants’ travel costs out of my student research allowance.

As described, five women had agreed to take part, with one additional member agreeing to be involved after receiving information on the research from the course facilitator. However one of these women dropped out later as she wanted to attend a course held at the centre on the same day. Her place was taken by a woman attending the women's group meeting that was held in the morning prior to the focus group session in the afternoon, and whom I had not previously met<sup>59</sup>. Five were in their late forties and above, and one was twenty-five.

I had the opportunity to spend time with the focus group participants during the women's group meeting. This meant that both they and I had a chance to talk. I was able to observe them and their interactions with others, which proved useful during the focus group. I was thus able to identify the most, and least, talkative members of the group, and who I might need to be more 'sensitive' with. For example, one woman appeared to become quite irritated if others invaded her space, and I did not push her to move closer when she chose to sit slightly outside the circle during the focus group.

Formal signed consent was gained immediately prior to the focus group. It is generally recognised that when researching with people who have learning disabilities, gaining consent requires extra consideration (Rodgers 1999). This includes making a particular effort to make sure that participants understand both what the research is about and what they are consenting to. Consent was formally obtained using a typewritten sheet (Appendix Five) outlining the participants' rights (for example not answering questions if they did not want to) and what they could expect (for example confidentiality)<sup>60</sup>. The form also gave the participant the opportunity to indicate whether or not they understood (by circling a 'happy' face or a 'sad' face). It was also designed to be signed by both the participants and myself. I sat with each participant, reading out and explaining each point further if they asked me to, or if I felt that they might need further information. I was prepared to audio-tape consent if anyone was unable to sign

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<sup>59</sup> This woman had received the information sheet from the group facilitator, and I talked through this sheet with the participant prior to her taking part, as well as going through the consent sheet. However, I now consider that including her may have been a mistake, mainly because of the lack of time she had to consider whether or not she wanted to be involved (the other participants had informally agreed to take part three months' previously, giving them time to change their minds).

<sup>60</sup> The form, and consent process more generally, was informed by the British Sociological Association's *Statement of Ethical Practice* available online at: <http://www.sociology.org.uk/as4bsoc.pdf>.

the form. All the participants were able to sign, and two participants indicated a 'sad' face on their forms – this was in answer to the question 'have you been given a copy of the handout'<sup>61</sup>. The two participants who had not attended the first session agreed that they understood what was involved and wanted to participate.

Despite this I felt that some of the women may not have fully understood their role within the research. For example, one consistently told me that she did not like talking about sex, and I felt that she might not have fully realised that that was what we would be discussing<sup>62</sup>. One participant contributed virtually nothing to the session, keeping her head down and only communicating to ask if it was 'okay' to go and get a drink, and to ask if I liked swimming. I occasionally checked to see if she was 'okay' (she said she was) and I told her it was 'okay' just to listen. This participant was the youngest, and it may be possible that this was a factor in her not contributing. Additionally, I sensed that she was also the least 'knowledgeable' in the group, and the most likely to be 'left behind'. Another member of the group said little but seemed to understand what was being talked about, and responded when prompted. A third member of the group also contributed relatively little, and about two-thirds of the way into the session admitted that she sometimes did not understand what we were talking about. Although this 'silence' might have been explained by group dynamics, it might also be explained by the 'sensitive' nature of the topic discussed. Although Kitzinger (1994) and Farquahar (1999) have argued that focus groups can facilitate an 'opening-up' on sensitive subjects like sexuality, as mutual support is available, it is also likely that talking in a group might be daunting for some participants. Despite this, all participants appeared to attend willingly, and all had been given the opportunity to 'back out' of the research at any point.

### *Topic Guide*

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<sup>61</sup> The facilitator had, in fact, included handouts with the letters about the research that she had sent to those women's group members who had not been in attendance on my initial visit, so it is likely that all attending had copies, but that these two women had lost theirs, or forgotten that they had them.

<sup>62</sup> This respondent was the one recruited, by the facilitator, during the women's group held that morning. This underlines the way in which including this respondent in the focus group might have been a mistake.



The topic guide content (Appendix Six) was based on the need to identify the sources of information on sexuality, and related accounts of sexuality, that participants came into contact with: ‘where’ and ‘what’? The women were asked to identify where they learnt about sexuality (or not), and I used two examples – contraception and ‘fancying’ to explore emotions and relationships as well as the physical aspects of sexuality. I also asked them to consider situations where they might not (or could not) talk about or learn about sexuality.

Questions were open-ended to stimulate discussion and were intended to be non-leading – to help ensure that the women expressed *their* views (McCarthy 1998b, Swain *et al.* 1998), and were relatively unbiased by my opinion. Nevertheless I acknowledge that interviewers (or focus group facilitators) do affect the way that interviewees (or focus group participants) respond to questioning (Lee 2000), and that some argue for ‘closed-questioning’ with people with learning disabilities, on the basis that this makes it more comfortable for those who have difficulty articulating their thoughts (Booth and Booth 1996, Lloyd *et al.* 2006, Owens 2007). The topic guide also included probe questions (Fielding and Thomas 2001), aimed at eliciting further information on each topic. The language I used was intended to be clear and understandable to a group of women with mixed intellectual abilities – although as I have already indicated, some did appear to get ‘left behind’, and throughout the research I sometimes had to rephrase my questions when I realised I was using ‘difficult’ language. I tried to make questions ‘strong’ enough to get information about sexuality, but not so strong that they might offend participants or put them off speaking. In practice the topic guide was used very loosely and not all the questions were asked. This experience was similar to Brigham’s (1998:147) who described her research process as more ‘fragmented’ in practice than anticipated.

I included some visual material to help me explain my questions (Lloyd *et al.* 2006) – I used the leaflet from the *Sex, Love and Relationships* course that I wanted to discuss as part of the focus group, and a line drawing of different kinds of contraception). I also used a flipchart with symbols attached<sup>63</sup> which I made notes on. Use of the visuals and flipchart also helped to break up the session.

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<sup>63</sup> These symbols included family, friends, baby, man/woman, house, day service, and long-stay hospital.

### *Implementation*

It is suggested that interaction is one of the main reasons for conducting focus group research (Albrecht *et al.* 1993, Carey 1994, Kitzinger 1994, Morgan 1997), which allows us to explore the similarities and differences in peoples' opinions (Kitzinger 1994, Morgan 1997, Kitzinger and Barbour 1999). Generally, the group tended to agree on much of what was discussed – often adding to each other's comments. On one occasion a participant seemed to change her opinion when another expressed an opposing one (Albrecht *et al.* 1993, Carey 1994, Morgan 1997); the first participant said that she felt that sex between non-disabled people and disabled people was wrong, but when the second participant suggested that 'everyone's entitled to a love life', she replied 'oh they are, they definitely are, really.' This suggests that whilst focus groups give researchers the opportunity to explore differences in opinion, it is also possible that these differences can get 'ironed out'. These two participants often spoke in tandem, possibly because they knew each other well, and because they were intellectual peers (or appeared to be). Despite this, they spoke to *me* rather than to each other, as did the other participants. Thus, the focus group failed to fully gain the interactive benefits that this method can offer, as well as the shift in power that this might represent. On a couple of occasions the women did begin to converse with each other – most particularly when they talked about a gay character in the television soap *Coronation Street*, and when they talked about a disabled woman featured in the press who had a child.

In relation to running focus groups there is always the potential that particular members will dominate the group (Krueger 1994, Greenbaum 1998). In my own case, members were drawn from an existing group who, it is likely, had already established particular ways of interacting with each other. Whilst trust might be a feature within the group, there is also the possibility that participants will know who *not* to trust, and will not 'open up' on sensitive subjects in front of them. There is an additional tendency for people to censor what they say in front of others they know in order to 'keep up appearances' with those they have an ongoing relationship with. Using an existing group

therefore can have both positive and negative consequences (Carey 1994, Kitzinger 1994, Kitzinger and Barbour 1999).

However, an awareness of group dynamics at the planning, implementation and analysis stages helps to counteract this possibility. Techniques like redirecting questions and using body language (like using eye contact to break contact/make contact, and turning away from dominant members and turning towards less dominant members) were used to try and increase contributions from less dominant participants. Despite this the two women just described dominated the group, and as other members tended not speak, even when encouraged, this continued. As already suggested, I felt this was partly exacerbated by the mixed intellectual ability of the group. It was also clear that the two dominant members had had more experience of telling their stories to other people (one at least had done so on the behalf of the organisation). The most dominant member of the group used relatively sophisticated language such as ‘vagina’ and ‘caesarean’, and helped me to explain what ‘media’ meant to the rest of the group. As this person also talked at length it is possible that others may have felt ‘left out’, even afraid to speak in case they sounded less knowledgeable than they felt they should be. These difficulties point to the important role that individual interviews can play, particularly in exploring sensitive subjects, where differences in personality between participants are removed, and differences in experience can be dealt with by changing the way that questions are asked, and adjusting questions according to the individual’s level of knowledge.

### *Analysis*

The audio-recording of the focus group was transcribed and read through, and initial observations were handwritten onto the transcription. It was then coded (Knodel 1993, Frankland and Bloor 1999, Fielding and Thomas 2001, May 2001), using the general themes indicated by the topic guide. Further codes and subcategories were added as themes emerged, and notes were made of conversational observations – interactions, jokes and so on. Kitzinger argues that these aspects of conversation can ‘tell *as much*, if not, *more* about what people ‘know’ than words themselves, and that this is a particularly beneficial aspect of focus group research (1994:109, original emphasis).

Silences were also noted. As Hyams (2004) argues, silences are not simply ‘absences’: the researcher has to ask what these silences mean (including the possibility that the interviewee is challenging the researcher’s right to ‘know’ particular kinds of information).

Using my initial coding, I drew out the most obvious themes, for example that sexuality, in respondents’ eyes, was not talked about within families; that sexuality was a ‘negative’ thing; and that men and women experience sexuality differently. I also highlighted points for further exploration, for example the various roles of families and services in relation to sexuality, and respondents’ conflation between sex and marriage/sex and children. I used these alongside my observations on language, level of knowledge about sexuality, and the influence of group interaction such as consensus (Carey 1994) to develop a general interview guide (Appendix Eight). Although mainly influenced by content (what was said), the analysis also took into consideration conversation – how things were said (jokingly for example, or in response to me/someone else, or in deference to somebody else’s opinion). By paying attention to the conversational aspect of the exchange I was able to contextualise the data (the meaning of a statement changes depending on whether it is said in a happy way or an angry way, for example), analyse the validity of a statement (the way I asked a question or a change of opinion in favour of someone else’s would affect this), and map the way in which interaction was involved in the creation of data.

As suggested, one of the key aspects of the methods used was the way in which they allowed for respondents introducing issues of relevance to them. Interestingly, the women came up with useful aspects of the topic that I had failed to consider. One suggested that computers could be used to learn about sexuality for example. She also challenged my own presumptions when we discussed the role of parents in helping women with learning disabilities to learn about sex and sexuality, by talking about her experience as a parent teaching her own children about these things.

## **Interviews**

### *Planning and Implementation*

The following charts show some general demographic details in relation to interviewees:

Table 1: Breakdown of interviewees by age

| <i>Age of respondent</i> | <i>Number of respondents</i> |
|--------------------------|------------------------------|
| 20-29                    | 4                            |
| 30-39                    | 1                            |
| 40-49                    | 2                            |
| 50-59                    | 6                            |
| 60-69                    | 2                            |
| 70+                      | 1                            |

Table 2: Breakdown of interviewees by residential status

| <i>Lived at home with parents</i> | <i>Lived in supported environment</i> | <i>Lived with partner (in supported environment)</i> | <i>Lived alone</i> |
|-----------------------------------|---------------------------------------|--|--------------------|
| 2                                 | 9                                     | 1  | 4                  |

Table 3: Breakdown of interviewees in relation to their experiences of intimate relationships

| <i>In a relationship<sup>64</sup></i> | <i>Not currently in a relationship</i> | <i>Previously in relationship (of those not currently in a relationship)</i> |
|---------------------------------------|--|--|
| 2                                     | 14                                     | 9  |

Interviewees were aged between twenty-five and seventy-eight, with most living in a twenty-four hour staffed supported environment (such as supported living or residential care, with one living in an adult placement). The majority (fourteen) of the respondents were not currently in a relationship, and of these, five had not *previously* been in a relationship<sup>65</sup>.

<sup>64</sup> 'Relationship' as defined by respondent.

<sup>65</sup> Having a relationship was not necessarily associated with sex.

All interviewees were asked where they wanted to be interviewed (including the options of at their home, at the university, or at the centre). It was not assumed that just because the women might be more familiar with the home setting or the centre that they would also feel safe to talk there. Around half of the women chose to be interviewed at home, and half at the centre. Two chose to be interviewed over lunch in public settings. This made interviewing difficult due to the sensitive nature of the subject, and the busy nature of the locations chosen. One respondent chose not to have her interview audio-taped, which made the issue of noise less problematic (we were in a café). The other interviewee was audio-taped, but we sat in a quiet part of the room (a pub). Neither respondent wanted to talk about sexuality in any detail, but it was unclear whether this was because they found this difficult in itself (what they said suggested this, with one becoming increasingly quiet as the interview progressed and I had begun to ask about relationships and sexuality), because of the location, or both.

Interviews in respondents' homes usually took place in the bedroom (if there were other residents in the house), or the living room (if living alone, although on one occasion this occurred with support staff present, but elsewhere in the house). Using bedrooms as interview locations was not ideal, as these might be seen as 'private' spaces. It was not a situation I felt particularly comfortable with, and although respondents themselves appeared to be, it cannot be assumed that they were. For this reason I always asked respondents if they were happy with this option, and would not have conducted the interview if I had thought that they were not. I would suggest that their apparent lack of discomfort in this arrangement was influenced by the way in which staff were likely to enter their rooms on a day-to-day basis, and thus my own presence there seemed relatively 'normal'. Additionally, other locations were associated with problems: interviews in respondents' homes were more likely to be interrupted (by staff, other clients or phone calls), and where others were in the building I was particularly aware that they might be able to hear what the respondent and I were saying, and that this might dissuade respondents from talking about sex and relationships, or their living arrangements (including their relationships with staff or other householders).

Interviews at the centre took place in a pre-booked private room. On one occasion an interview took place in the library, as all the rooms had been booked or were

being decorated. This was my first interview at the centre and I had not booked a room, as I had been told that there was one almost always free (a mistake in hindsight, but one that taught me to be prepared). Although the library was rarely used, two service users entered the room towards the end of the interview, which then had to be terminated. A second interview later took place.

My supervisors alerted me to the way in which interviewees might talk to one another about the questions they had been asked, perhaps ‘preparing’ other respondents prior to their interviews or giving them cause for concern<sup>66</sup>. Although I used a similar interview schedule for most first interviews, I did not always follow the same line of questioning, tailoring the interview to the individual. Where I used the same interview questions for different participants I did not, despite my acknowledgment of the ‘storied’ nature of interviews, necessarily want participants to have ‘practised’ what they were going to tell me, if only because this would lead to ‘scripts’ that might not ‘fit’ with the questions I was asking. Secondly, with my ‘tailoring’ of the schedule to each participant, I tried to gauge ‘how much’ a participant could answer comfortably, so that whilst with some I felt that I could ask about sexual practices or experiences, with others I felt I could not. It was therefore unhelpful for me to have participants worrying about what they might be asked. Whilst I am unsure of the extent to which participants discussed the research (or not), during the monthly meetings their references to it were limited to comments like ‘Elizabeth’s the student, she’s been asking us some questions’, or ‘She’s interviewed *me*’ (which might have helped in the ongoing recruitment of individual women to the research).

All but one interviewee was audio taped. This respondent refused on the basis that she did not like hearing her voice on tape. I reassured her that she did not need to listen to the tape, that I would be the only person listening to the tape, and that I was uncomfortable with hearing my own voice on tape. I also pointed out that if I had her voice recorded, I would be able to use exactly what she had said rather than what I thought she had said. However, the respondent did not change her mind and written notes were taken. I thus focused on noting down selected verbatim speech in an attempt

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<sup>66</sup> Due to the sensitive nature of the topic, and the fact that some women might have had negative experiences in relation to sex and relationships, or indeed no experience of sex and/or relationships.

to make the data as accurate as possible (Fielding and Thomas 2001). Audio recording worked well although, on one occasion, the acoustics in the bedroom of the respondent I was interviewing caused most of what we had both said to be difficult to decipher. A second interview with this respondent, with more attention paid to the position of the recorder and the use of an external microphone, helped to remedy this situation.

All interviewees were made aware, both formally through the written consent process and informally when necessary, that they could end an interview at any point. Only one respondent did this. This respondent, from my previous observations of her, tended to take frequent breaks from activities or left them before they were completed, so I expected her to ‘break off’ during interview. To try and work with this I asked her if she would be comfortable staying longer when she asked if we had finished, but did not ‘push’ this, allowing her to end both of the interviews she participated in when it felt ‘right’. This respondent also made it clear that she did not want to talk about sex in her second interview (she related this to her experience of being raped, which she had talked about at length already) saying: ‘I don’t want to talk about it (sex), I got forced to have sex once. I don’t want to talk about that’ (so we did not)<sup>67</sup>.

### *Interview Schedule*

As suggested, interview questions (Appendix Eight) were shaped by the focus group data, as well as by the research question. The schedule was refined over repeated supervisions, and over a six-month period. Eventually I chose to divide the questions up into an initial section focusing on background (family, where respondents lived/had lived, what they did with their time, and why they attended the women’s group) (McCracken 1988), a second section looking at where they learnt about sex (who from, did they talk to people about sex, had they been on the *Sex, Love and Relationships* course), a third section looking at their experiences of sexuality and relationships (how they felt about sex, had they had boyfriends, were they/had they been married, did they have children), a fourth section looking at their views on sexuality (including same-sex

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<sup>67</sup> The purpose of the second interview was to gain some contextual background, as this respondent, despite saying that she did not want to talk about sex, had talked about the rape at great length in her first interview, almost to the exclusion of any other aspect of her life.



relationships, sex outside of marriage, single parents), and a final section looking at how they thought people with learning disabilities were viewed by others in relation to sex and sexual relationships. I placed questions about sexuality, particularly their own, well into the schedule to 'ease' respondents into talking about this more 'personal' area of their lives (Ackroyd and Hughes 1992, Lee 1993)<sup>68</sup>.

I 'rehearsed' the interviews with two ex-colleagues (support workers who had worked with people who have learning disabilities), as they would be able to comment on the suitability of the language used. These were male colleagues, which might have influenced their responses. However, any gendered differences were difficult to identify<sup>69</sup>.

As the interviews progressed the questions continued to be developed, not only to improve their clarity, but to take into account what respondents said, including the topics they introduced. For example, I had not initially included a question that asked a respondent to say whether they had a learning disability or disability. This was because I felt that this was a sensitive issue given the stigma attached to these labels (Harris 1995, Todd and Shearn 1997, Finlay and Lyons 1998, Rapley *et al.* 1998, Craig *et al.* 2002, Jahoda and Markova 2004). Craig *et al.*'s (2002) UK research (that included a focus group of six men and women with learning disabilities), showed that respondents became 'awkward' when this term was used, often changing the subject or ignoring the question they had been asked. On the other hand, Davies and Jenkins (1997), who interviewed sixty young adults with learning disabilities in the UK, suggested that their respondents showed no discomfort when researchers explored their understanding of 'mental handicap' and 'learning difficulty'. In my own study, this question did, on reflection, seem necessary to help clarify responses related to questions on how learning

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<sup>68</sup> Although Homan (1991) argues that this does not minimise the ways in which such questions can be invasive.

<sup>69</sup> The questions were also more generally discussed, as the schedule evolved, with two female friends who had worked with people with learning disabilities, but who were unable to commit to an 'interview'. The only access that I had to women with learning disabilities at that point was via the organisation where the women's group met; my target group for the interviews 'proper'. I did not therefore 'rehearse' the questions with women with learning disabilities themselves. It is also important to note that the schedule was never 'finished' in that it continued to develop in response to each interview. In this sense the production and development of the schedule was an iterative process that began with the focus group, was developed over several supervisions with supervisors, 'rehearsed' with people who had worked in the learning disability field, and continued to develop during the interview process.

disability was perceived by non-disabled people (was the respondent speaking as someone with a learning disability, or as someone outside of that label?) and to help contextualise responses (were their responses related to their awareness of the label 'learning disability' or not?)

Although for the initial 'wave' of interviews a relatively standard (yet flexible) schedule was used, the second wave interviews were tailored towards each participant in order to follow up on comments they had made, and to ask additional questions based on developing themes that had been influenced by interviews with other women (see Appendix Nine for an example).

I thus used an in-depth, semi-structured and flexible approach (Ackroyd and Hughes 1992, Fielding and Thomas 2001). Questions were as open-ended and non-directional as possible (McCracken 1988) and included relatively straightforward and simple language. This was supplemented by the visual material used with the focus group, plus some line drawings from education packs on sexuality specifically for people who have learning disabilities (although these were only used on three occasions, and not all the visual information was used).

Questioning elicited a range of responses, from one respondent talking at great length after every question, to responses that were a sentence or two (most respondents answered like this), through to 'yes' and 'no' responses (which tended to be used consistently by specific respondents, including one who also used other single words to answer questions). Despite probing further with those respondents giving shorter or yes/no answers, most did not speak at length.

One respondent spent most of her interview talking about the abuse that she had experienced, and on this occasion I made the decision to abandon the schedule on the basis that it would have seemed insensitive to ask the respondent unrelated questions, thus detracting from the importance of what she was saying.

Simpler language was used with one participant, with less open-ended questions. This participant was keen to take part but was difficult for me to understand<sup>70</sup>. More often than not I had misunderstood what she had said, and the 'right' meaning became

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<sup>70</sup> This was due to the way in which it was physically difficult for her to form words, rather than her ability to describe things.

clear after asking her to answer in a different way (although sometimes I had to accept that I did not understand, apologise and 'move on'). In order to further be sure of this participant's answers, I repeated her answers back to her for confirmation. Where I was not clear on her answers, I did not use the data.

I considered asking her if she would like a support worker to be with her to help me understand her, but decided not to do this on the basis that I felt it was important that the respondent communicate for herself, especially in relation to feelings. In practice the interviewee included her support worker twice during her interview to clarify practical points (her age, how long she had lived in her home and how long she had been married). The support worker was elsewhere in the house and was called in where necessary. My decision not to have a support worker in the interview was validated to some extent when in discussion with the respondent about where she might like to be interviewed, another support worker (not the one involved in the interview) suggested that the respondent would prefer to be interviewed at home, in direct contravention of what the interviewee had communicated to me earlier. It was clear that that particular support worker was used to making assumptions about this respondent's wishes.

As Booth and Booth (1996) suggest, people with learning disabilities sometimes experience difficulties understanding concepts. Despite the effort made in designing the interview schedule to try and explore concepts using simple language, many respondents had difficulties with some interview topics, and in particular, how they thought other people might feel about them having relationships. It appeared that those who found this question difficult had difficulties seeing beyond their own experiences and viewpoints. When, for example, I asked one respondent if she thought that people with learning disabilities had the same chances as other people to have children she said 'I don't know about that... I've thought about nothing like that.' Only one respondent consistently talked about how other people might view her, or view people with learning disabilities more generally. Many also found it difficult to trace where they might have heard particular opinions about sexuality, with some giving their own opinion and ending with a comment like 'that's what *I* think'.

As a novice researcher I also made mistakes when questioning respondents, for example asking more than one question at once. Although I used a schedule it was, more

often than not, a starting point for questioning, with most interviews taking place in a non-linear style in order to probe more deeply into interesting and important points that respondents had made, and with lines of questioning going backwards and forwards across the schedule. I frequently failed, in early interviews, to probe at these interesting points, and only identified my error when I transcribed the interview. Through this I learnt to be more aware of when and where to probe, and to be more confident in pausing at these points, rather than continuing with the schedule in an effort to complete it all. This meant that I was more able to access the 'in-depth' data that I was seeking. Both the development of the schedule, and the development of my interviewing skills, represented an iterative process in which my competence and confidence increased as the fieldwork progressed. Of significant benefit were the opportunities for doing second interviews: I knew how each respondent answered questions (and could tailor schedules accordingly), and what made them (and me) comfortable or uncomfortable. Respondents too seemed more open and at ease.

### *Analysis*

Initial thoughts and themes were noted down as soon as possible after the interviews (and were sometimes dictated into a voice recorder whilst driving home). The interviews were transcribed as soon as possible after the interviews had taken place. These transcriptions were read through, and were then annotated by hand, forming an initial analysis, with the annotations then typewritten into the transcripts. Copies of these were made, and were coded using coloured markers. Codes were based on question topics and some of the emerging themes. I then physically cut-and-pasted sections and quotes from each respondent's transcript into differently-themed transparent sleeves, sometimes using multiple copies to be placed into different sleeves as appropriate where data could be categorised in more than one way. At this stage there were around twenty sleeves representing different themes or strands to the data. These themes included topics such as 'family', 'services', and associated themes such as 'constraint', 'agency', and 'sexual knowledge'. (Whilst using a data analysis software package such as NVivo and N6 was considered, the small sample of respondents suggested that this would not be necessary.

I felt that the different – and physical – process of cutting and pasting the data, having spent months using a word processor, might give me a different relationship and perspective on the data. I had also been told during training in N6 that using software sometimes meant that researchers could become ‘distanced’ from the data. This influenced my decision not to use such software, although Silverman (2005) does argue against this view.)

I then began to write up particular quotes alongside analysis and interpretation into sections of writing that represented themes that seemed to fit together. Thus the act of writing blended with analysis and interpretation, and much of this time was spent trying to extract some kind of structure and meaning from the complexity of the data. This involved returning to the original transcripts a number of times, and included a second coding when all the interviews had been completed and transcribed, along the themes that had emerged since my original codes had been developed. This usefully illuminated particular aspects of the data that I had missed. Text was reshaped via electronic cut-and-paste several times. It was only through an iterative process involving writing, analysis, interpretation, and feedback from my supervisors, leading to deeper analyses, that some of the more complex themes became apparent.

This process ran alongside continued interviewing; as preliminary analysis began early, initial and emerging thoughts were also used to adapt and develop the interview schedule throughout the fieldwork. This process was particularly influential on the second wave of interviews as themes emerged in the analytical process. After completing the participant observation (see below) I began to include data from this alongside data from the original focus group into my writing. At this stage I was able to begin to work the data findings, analysis and interpretation into specific chapters.

Throughout the research process, I was aware of the arguments that research respondents with learning disabilities are more likely than others to answer questions in a way that approximates with the answers a researcher might seem to want to hear. (Rodgers 1999, Barr *et al.* 2003, Lloyd *et al.* 2006)<sup>71</sup>. This was dealt with by using open-ended questioning, repeating questions and asking questions in different ways when I suspected that this might be happening, as well as returning to these questions at second

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<sup>71</sup> Although this assumption might, it has been argued, presume ‘deficit’ (Goodley 2000).

interview<sup>72</sup>. Nevertheless, the possibility that acquiescence had not been eliminated was considered at the analysis stage. Thus, where I felt that acquiescence had influenced a respondent's answer, I did not include the data in the analysis. However, this underlines the power that I had as a researcher to use or not use respondents' comments (an issue I will return to later), and I acknowledge that I had to make decisions based on assumptions as to whether acquiescence was taking place.

## Participant Observation

Observations on the *Sex, Love and Relationships* course<sup>73</sup> helped to contextualise and give further information in relation to what focus group participants and interviewees had reported. Approximately half the focus group participants and interviewees had attended the course, with most being extremely positive about it. Participant observation on the course took place over four Mondays during October 2005, each session lasting for four-and-a-half hours, including lunch. The course itself ran for five days, but I was unable to attend on one of these (week three), although I later gained a verbal report on this session from the main course facilitator. Seven people with learning disabilities attended: four men, and three women. Formal consent from course participants was not sought, although they were made aware that I was there to observe the course<sup>74</sup>. This was because the main aim was to observe course content, and because where participants' comments were used, this would only be in a generalised way (e.g. what was recorded on each day for the course report).

Further information about the course was sought afterwards from the main course facilitator. The questions were 'How long has the course been running?', 'Has the

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<sup>72</sup> Lloyd *et al.* (2006) highlight, however, that changes between interviews might reflect a change in view rather than a lack of consistency based on acquiescence.

<sup>73</sup> Information on course participants, volunteer planners, facilitators and support staff can be found in Appendix Eleven.

<sup>74</sup> Despite this there was a tendency for participants to see me as a member of staff, with one participant approaching me to tell me that she would not be able to attend on a particular week. Since I was not eliciting information from participants in the same way as I would with interviewees (merely observing), this 'error' was unlikely to impact on the kind of data I would collect (other than when I approached participants for their overall impressions of the course, when they might have been more reserved than otherwise). Despite this, I was asked by another participant to pass on a 'love letter' to another participant, perhaps suggesting that I had taken on a status 'outside' of 'member of staff'.

course changed in any way over the years?', and 'Who has run the course in the past?' These questions were necessary, because any changes in course content or delivery over time would affect how the information I had gained during observation (and from the women's group facilitator, who had given me a previous course report to look at) contextualised what interviewees and focus group participants were saying about it. Apparently there was about twice as much material available to use on the course than I had observed<sup>75</sup>, although there had been few changes to course content over the five years that it had been running. There had been a number of staff involved in running it (I was given a list of nine). From what respondents had said, and through comparing the 2002 course report with what I had observed in 2005, the course appeared to cover similar ground in a similar way.

I also sought information about a women-only version of the course from two members of staff who (it had been suggested) had been involved in running it. This was not the case (the staff mentioned had not been involved) and I was unable to find out exactly what this course had included. Two interviewees had referred to this course, suggesting that they had discussed things like 'how to attract a man' and had had 'make-overs' on it. These activities seemed at odds with the content I had observed (it was not so explicitly gendered) and it seemed important to find out if these activities had actually been included. Whilst I was unable to find out if that was the case, I suspect that the women might have been talking about other courses (including a women-only course where the women did have make-overs).

The course content covered a range of issues. Most of the course was based on discussion and group work that did not involve a traditional 'teaching' format. Role play was used to explore particular issues (e.g. asking someone out, how to deal with institutional abuse), and included the volunteers and participants. More formal teaching was involved, however, with a question and answer session which was used to explore the facts about sex and the law, and a nurse visited for one session to talk about anatomy, reproduction and safe sex. A video, *My Choice, My Own Choice* was also used to explore sexual rights. (The video was described by participants as 'Eileen's Choice'.

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<sup>75</sup> Any additional topics to those I had observed were not identified.

It focused on the sexual and contraceptive choices of a woman with learning disabilities called Eileen).

Some discussion was dominated by the volunteers who had to be reminded by the facilitators that the course was for the participants. Despite this, participant engagement with the course was generally high, although one tended both to contribute less and to fall asleep at points (particularly after lunch). All participants appeared to become more relaxed and more communicative as the course progressed, and there was a general sadness on the final day that the course was coming to an end. One of the main reasons given by participants (as well as the focus group and interview participants) for attending was to socialise and make friends, and there was a sense, that by the end of it, participants had bonded with each other, the volunteers, the facilitators and myself.

On the final day I approached some participants to gain their opinions of the course, and this information was supplemented by the final evaluation of the course. This evaluation involved the facilitator asking questions about participants' feelings in relation to the course, which were recorded on a whiteboard (Appendix Thirteen)<sup>76</sup>. Information elicited by myself did not differ significantly to the information gained during the formal evaluation.

As suggested earlier, notes were taken when possible during sessions, and were added to as soon afterwards as possible (May 2001). These were based on an observation of what people did and how they interacted, and a description of the events that took place. These notes were annotated, and analysis was done via coding (using coloured markers), that related either to course content, or to the kinds of things that participants said (which were coded in the same way as the interview data). The observation data was added to interview data alongside focus group data about half-way through analysis of the interviews. This was because the majority of the important 'core' material was drawn from the interviews, and it seemed important to explore the themes within that before adding more contextual details.

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<sup>76</sup> This was likely to affect what participants said, as it required them to feel confident enough to speak, and to give their true opinion, without the relative anonymity of using a written form. However, this approach is a necessary one where participants might not be able to read and/or write.



## Ethical Issues

### *Consent*

People with learning disabilities are perceived to be a vulnerable group (Swain *et al.* 1998) and women particularly so. It is thus important that participants understand what they will be involved in – a particular issue with people who may have less understanding of, and less vocabulary than others (Booth and Booth 1996), in relation to sexuality.

I therefore paid particular attention to ensuring that respondents had as much information as possible about the research, in order for them to understand their rights in connection with it. As suggested, some respondents attended my initial presentation and all respondents were provided with an information sheet outlining the research (Appendix Three). Although an attempt was made to make it ‘accessible’ I did not wish to oversimplify what I was trying to convey. As Aspis (1999)<sup>77</sup> suggests, ‘accessible’ jargon-free literature often oversimplifies concepts in the attempt to simplify language. I was therefore concerned that oversimplification might also misrepresent my aims, and I produced the handout with the intention that wherever possible the participant could use it to discuss the research with someone who could read it if they could not (myself or the facilitator<sup>78</sup> if necessary) and clarify details they might be unsure of.

Consent forms (Appendix Five) were used, and explained to respondents prior to the focus group and interviews<sup>79</sup>. They included my commitment to maintaining confidentiality and anonymity as far as I was able, the right of the participant to withdraw from the research at any time and the right to refuse to answer questions at any time. However, McCarthy argues that formal consent is ‘often meaningless’ and a ‘token

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<sup>77</sup> Who has an intellectual impairment/is labelled as having a ‘learning disability’.

<sup>78</sup> The facilitator discussed this with me prior to the research commencing. Because she knew most of the women well, had discussed sexuality with them before, and had been involved in developing an information pack on sexuality, as well as having a good idea of the kinds of questions I would be asking respondents (she had seen the interview schedule at various stages because I valued her advice), both she and I were happy with her taking on this role.

<sup>79</sup> The same format of consent form was used for both focus group and interviews, although consent forms were used separately for focus groups and again for interviews if respondents were involved in both. I did not, however, use consent forms for second interviews, considering that this might be ‘overkill’. Additionally, some women seemed uncomfortable with the formal process of providing a signature (one woman did not know how to spell her name). However, I did verbally reiterate the contents of the consent form to respondents prior to second interview.

gesture' in this kind of research because signing a consent form is not in itself evidence that a respondent understands what the research and their role in it entails (1998b:144).

Swain *et al.* (1998) similarly suggest that we cannot rely on such codes and that consent should be a negotiated and continual process. This meant that I also maintained an informal consent process whereby I reminded respondents of their rights (including the right not to take part) outside of formal consent. This corresponds to what Knox *et al.* describe as 'informed consent as a process, rather than an initial agreement' (2000:56). Sin (2005:279) has persuasively argued that

...the type and level of consent required may differ at different stages of research and within any single stage. The changing nature of informed consent necessitates a reflexive approach to its engagement.

Humphries and Martin (2000) have highlighted that consent is not only concerned with the protection of respondents, but also the reputation of the researcher's university/employer and the wider research community. Thus the production of ethical guidelines might not have the respondents' protection as its primary consideration. Further Humphries and Martin suggest that such ethical procedures obscure the power relations inherent within them, and the wider research. Finally, Sin (2005:281) has argued that consent forms do not necessarily cover the ways in which research changes, particularly as an 'end product'.

It has been suggested that people with learning disabilities are more likely to agree with others because of the social conditions in which they have lived (McCarthy 1998b, Stalker 1998). This has implications on both the research data, as suggested earlier, and on whether the participants have really given their 'informed consent' to participate. Consent may therefore be based on a misunderstanding of what the research is really about, and the level of control that respondents have over the process (McCarthy 1998b, Swain *et al.* 1998). None of the respondents seemed to show an interest in controlling the research (despite the facilitator's concerns that those women who had been involved in research prior to this might want to be more involved). However, despite the consent process, I am unconvinced that all respondents fully understood what their involvement would mean. For instance, as suggested, many

respondents found it difficult to talk about sex and relationships (some simply would not), despite it forming the subject of the research and my making this clear to them. One interviewee was so upset by my questions in this area that I stopped the interview – which was a difficult decision because in doing so I was overriding her consent to participate. The difficult question of whether to include people with learning disabilities in research, on the basis that this group might be unable to give ‘true’ or ‘full’ consent, is highlighted by Lennox *et al.* (2005:303), who argue that the difficulties faced by researchers in relation to ‘the right to protection from unscrupulous researchers and the right to inclusion’, needs to be recognised and addressed.

### *Anonymity and Confidentiality*

All interviewee and focus group respondents were informed that I would treat any data they gave me with confidentiality. I dealt with this by ensuring all data and documentation included pseudonyms from the start. Real names and contact details were kept in a locked drawer, as were transcripts. I only took addresses and phone numbers if participants gave them to me voluntarily (I wanted to allow respondents as much control over their involvement as possible, given the lack of control they were likely to have experienced in other aspects of their lives). Some women chose to be interviewed at home, and I necessarily had their addresses if not their phone/email details. Others chose to be interviewed at the centre, with most of these women choosing not to give me their details. The group facilitator agreed that should I need contact with any of the respondents who had not given me details, she would contact them on my behalf.

Anonymity was discussed during the consent process, however I could not ensure this fully, and made this clear to participants. Being members of an identifiable group in a specific location that has its own distinguishing features also made it more likely that anonymity would be difficult to maintain. Using focus groups also have disadvantages in this respect. Whilst group participants were asked to keep information exchanged confidential, this confidentiality could not be ensured (Carey 1994, Kitinger and Barbour 1999), and thus the focus group, whilst potentially supportive, was not necessarily ‘safe’.

Although initial access had been discussed in terms of the organisation being publicised (for example I might write alongside the respondents in practice-based journals that would highlight the existence and work of the group and organisation), I made a later decision not to use its name on the basis that the data I had collected was more sensitive than I had originally anticipated, and I wanted to maximise respondents' anonymity. All respondents' names were changed, and partners, friends and relatives were referred to as 'partner', 'friend', 'mother' and so on.

Disclosure of certain circumstances (such as instances of current abuse) places the researcher in a position of responsibility. Prior to interviews this possibility was highlighted by, and discussed with, my research supervisors as well as a postgraduate colleague who had had experience in this area. It was agreed that breaking confidentiality in this instance was a necessity, and that this should be made clear prior to interview, and again at the point of any disclosure. Although respondents disclosed abuse, all instances were in the past, and had been dealt with<sup>80</sup> at the time (e.g. care managers and/or police had been involved).

### *The Researcher Role*

Feminist research in particular (for example, Oakley 1981, Stanley and Wise 1993, Harding 1987, Reinharz 1992) suggests that researchers should be open about 'who they are' within the research context, paying particular attention to the issue of researcher power<sup>81</sup>. As a non-disabled, middle-class, relatively highly-educated woman, my background differed considerably from the women in the group, and as suggested, I was acutely aware of these differences.

Although respondents were aware of my role as researcher<sup>82</sup> I chose not to divulge information about myself unless respondents asked me about this. This was not because I did not want to be 'honest' with respondents, or felt that my own background was irrelevant (to the contrary I believe that researcher backgrounds and identities are

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<sup>80</sup> As I will suggest later in this thesis, this might not have meant that that these instances were dealt to the satisfaction of respondents.

<sup>81</sup> Although Humphries and Martin (2000) argue that this does not *eliminate* power differentials between researcher and respondent.

<sup>82</sup> I made it clear that I was learning about this role with their help.

inextricably interwoven into the research process at all stages). I felt that firstly my background might intimidate women who had not had the same opportunities as I had, and secondly that it might seem egotistical to start talking about myself when the research was focused on respondents. Only a handful of women asked me anything about myself. One interviewee did this throughout my interview with her and I attempted to both answer her questions politely *and* steer her back to the interview. One respondent confided in me regularly at the monthly meetings on her experience of abuse. She suggested that no one else was available to listen and that I was the only person she knew that understood/accepted her need to talk. This, she said, was on the basis that I too had experienced abuse within a relationship, a fact that I had divulged fairly early on in our relationship. This altered our interactions as researcher and interviewee (she evidently felt more comfortable discussing her experiences with me, although I also wondered whether giving her this information had been the 'right' thing to do), and might also have been influenced by my nominal 'membership' within the women's group, as discussed earlier.

### *Talking About Sensitive Issues*

As I have already suggested, disclosure of abuse or similar circumstances may lead a researcher to break confidentiality (McCarthy 1998b). Additionally, advice or information may be sought about abuse or sexuality more generally. The researcher should also be prepared for the possibility that the research may cause individual participants distress (McCarthy 1998b). Prior to interviewing participants I drew up a list of resources (books, leaflets, videos/DVDs and the names of organisations) in case respondents required information on sexuality. One respondent suggested that she had little opportunity to discuss an abusive relationship and I was able to give her information on people that she could talk to (although she did not choose to take this further during the time that I knew her).

Abuse was a topic that I deliberately avoided asking respondents about, particularly because McCarthy (1999) and others had covered this area. Additionally, I did not initially see abuse as central to the research question. As interviews progressed

however, it became clear that abuse was an issue for a number in the group and I began to see how abuse affected the ways respondents felt about sexuality (for example in the subsequent avoidance or fear of sexual activity and relationships after experiencing it). A decision was made not to introduce abuse as a topic, but where it *was* brought up by participants, to ask specifically about the resources and support that had been available to them (for example counselling services), because a lack of such support appeared to be a distinct theme in relation to the abuse that had been reported.

Discussing abuse was difficult on a number of levels. Most obviously I did not want to upset respondents. More importantly, I did not want respondents to either regret the fact that they had told me about their experiences, or to suffer emotionally afterwards (and although these would be difficult effects for me to predict or control I still felt a sense of responsibility on leaving the interview setting). Whilst the literature on ethical guidelines tends to side-step the emotional well-being of research respondents, particularly after research has taken place (Sin 2005), this is an important aspect of research to consider (Humphries and Martin 2002). Having a list of contacts and resources to hand, as well as the support of the group facilitator and in some cases the women's support workers (who would be there *after* interview and/or research involvement<sup>83</sup>), helped here. Despite this, on two occasions where abuse was discussed I felt concerned enough to provide respondents with my home phone number<sup>84</sup>, but on neither occasion was it used. One of these respondents asked that I visit her again (I was only the second person to have been told about her thirty year experience of abuse)<sup>85</sup>.

In addition to the subject of abuse, discussing sex in interviews (not just in relation to sexual abuse, but generally) was sometimes extremely difficult. Firstly, many

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<sup>83</sup> I also produced an information sheet for support staff which I gave to respondents to pass on to staff if they wished to do so (some chose not to as they wanted to keep their participation in the research private). I also offered to talk to support staff about the research if respondents wanted me to (none asked me to do this – no reasons were given and I thought it might be intrusive to ask why).

<sup>84</sup> Something I felt reluctant to do on the basis that it might make withdrawing from the research field difficult.

<sup>85</sup> I struggled with this on the basis that whilst I was wary of continuing relationships beyond the research, I was also mindful that this interview was probably, for her, a highly significant event. I did not see her at the women's group again before it ended, and decided to write to her (she was able to read), including my home address and phone number, inviting her to contact me if she needed to. I did not hear from her and did not feel that it was appropriate to write again on the basis that although she had asked me to visit her on the day of the interview, she might have changed her mind since. Despite this decision I am still unsure of whether this was the 'right' thing to do.

women appeared to dislike talking about sexuality, despite me making it clear that this was the topic I would be asking them to talk to me about, suggesting as I have already discussed, that the consent process might have been flawed, or that respondents had a limited understanding of the term. It is also possible that their interpretation of it was different to mine. Secondly, as suggested, some women had experienced physical and/or sexual abuse, and although most talked openly about this, it felt like I was intruding on a painful aspect of their lives. There was also the ever-present possibility of the disclosure of current abuse; if such abuse occurred, and if the respondent did not want the details of this taken further, they would necessarily have been asked not to discuss it. Thirdly, I was aware that asking someone if they had or had previously had a boyfriend, husband and children when they might never have had the opportunity to have these might be upsetting (and one woman did become upset and cry when I asked her about these things). Finally, I also realised that I had difficulties asking about sex – something I had not expected. I found this particularly difficult when asking respondents about current relationships as this felt intrusive. I was also wary of embarrassing respondents. This was particularly so with the oldest respondent (aged 78) who ‘closed down’ as soon as sex became a topic for discussion. When I was able to be open about sexuality, in many cases respondents were also open. On the other hand others immediately ‘withdrew’: a number of respondents began to ‘close up’ (in one case to the point where talking about anything was difficult, and in another to the point where the respondent was in tears, it seemed wrong to continue, and I terminated the interview, as highlighted earlier).

It is important to note that such discomforts around exploring these issues, caused mainly because of the need to explore sensitive topics whilst ensuring that this was done ethically, would necessarily impact upon the kind of data gathered. Whilst I argue throughout this thesis that there was a ‘silence’ on sexuality in the data (an argument based on a number of reasons, that included the way in which respondents found the subject a difficult one), it is likely that to some extent at least, such a ‘silence’ was caused or exacerbated by my own wariness in exploring particular topics, including sexual ones. Nevertheless, this wariness was, in part, more evident in the early stages of the research. My supervisors had noted my lack of confidence in engaging with the topic of sex at this point of the fieldwork after reading transcripts of the first two interviews I

conducted, and suggested that respondents might be more open than expected if I was less 'sensitive' about the subject myself. In subsequent interviews I ensured that I directly referred to sex, sexuality and sexual relationships, albeit pulling back from such discussion where that seemed appropriate. Like other aspects of the research, my confidence grew as the research progressed.

In addition, I had a further opportunity of re-interviewing one of those first interviewees, who had, despite my own difficulties with the subject matter, been open and apparently comfortable when talking about her sexual life. For example, she described the ways in which she enjoyed 'teasing' her husband sexually. This apparent comfort was evident too with a small number of other interviewees, suggesting that although I may have been careful in how I approached the subject-matter, at least some interviewees felt that they could talk openly (Charlotte, for example, spoke graphically about sexual experiences, both wanted and unwanted). Further, whilst my own discomforts with particular topics were likely, as suggested, to have affected the data, I would nevertheless argue that the overall 'silence' I felt existed was 'real', on the basis of the extreme reactions that some respondents had to any discussion of sexuality, including relationships and emotions.

The impact of these women's stories was stronger than I had expected. Listening to what they had to tell me made me feel both angry and helpless – their experiences were in the past but their negative emotions in relation to their abuse were still strong. All these women suggested that they had fewer chances to express their feelings or describe what had happened to them than they would have liked. Such opportunities might have helped them to understand and handle the feelings that they had had about their experiences. After these interviews I found it hard to go back to other aspects of the research. Although I had the opportunity to discuss one such interview with a supervisor a day or so after it had taken place, I felt unable to discuss what I had been told with others, despite encouragement from my supervisors to talk to them and others if I could. However, having contact with postgraduates who had been through similar experiences, and being able to talk with them 'in the abstract' about having this kind of experience, was invaluable.



Another difficulty in relation to abuse was raised by the need to introduce it into the thesis without shocking or upsetting those who might read it. Although I chose not to include details of abuse, I found it difficult to write in a way that avoided being ‘harsh’. This led me to considering whether ‘rape’ was a more shocking word to use than ‘abuse’, whether it would help to begin by using a ‘softer’ sentence before, that led up to me using words like ‘rape’ or ‘abuse’, and whether a discussion within the methodology chapter of the thesis would help to make such references less upsetting when they came up in the later data chapters. There was also the temptation *not* to soften this information, to say ‘this is the “reality” for these women, so why make it easy for others to read about?’

I had additional concerns in relation to respondents’ wider experiences that made interviewing difficult. These included asking respondents about their families – they might be dead, they might not have contact with family, or the family context might have been the site of abuse (McCarthy 1999). For example many people with learning disabilities I had worked with previously had not had contact with family members, and during interviews I found that two of the women had experienced sexual abuse within their family.

### *Withdrawing From the Field*

It has been suggested that people with learning disabilities may have expectations of friendship with researchers after research is completed (Stalker 1998). By approaching an existing group of women, ensuring that back-up support was available should it be needed from the group facilitator (as discussed earlier), and being clear about my role (through, for example, the information sheet provided to them) I hoped to minimise this possibility.

After concluding the interviews I continued to attend the group’s monthly meetings, but began to attend less frequently (every other month). All the women still attending (some had stopped) were aware that I had concluded my research with them at this point, and had been given the opportunity to discuss their involvement in the

research (for example to suggest that particular data not be used<sup>86</sup>). I had also approached those women who had given me sensitive information and checked that they were comfortable both with what they said, as well as their subsequent feelings about ‘opening up’ to me, where this was possible. It was at this point (December 2006) that the organisation hosting the group, decided to end its support<sup>87</sup>. I received email notification of this from the group facilitator who said that one final women’s group meeting would take place. I was able to say goodbye to only a small number of the women who had taken part in the research as most did not attend. Despite ‘winding down’ my involvement with the group, I found this abrupt end difficult, feeling particularly responsible for those women who had told me sensitive details about their lives. I had also become quite close to some of the members (both those I interviewed and those I did not).

### *Returning To the Issue of ‘Voice’*

As suggested at the beginning of this chapter, it was particularly important to me that my research reflected the views of those researched, whilst also recognising the way in which research reflects a construction between researched, researcher and reader. Once analysis and writing-up began, it became clear that representing ‘voice’ was far from straightforward. Firstly, it became clear that many women were unable to ‘see’ that they had fewer choices than others, and less independence<sup>88</sup>. Leaving out this data on the

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<sup>86</sup> I had given respondents time at the end of interviews to discuss this if they wanted, and had made it clear that they could ask me not to use particular aspects of the data at any stage. I also made it clear that I would be available to talk at subsequent monthly meetings. I made sure that I spent time with each respondent at these events, usually giving them feedback on how the writing was going, to give them the opportunity to ask me about it if they wished to. All women had my university contact details (phone number, address and email address). None suggested that I could *not* use data previously given, although as I will discuss, one respondent had suggested that particular information included in her interview should not be used, and reiterated this at later informal meetings.

<sup>87</sup> They had decided to withdraw financial support (for example paying for the group facilitator, and for providing taxis to and from the meetings), preferring to use the money on other projects within the organisation. It was not clear why the group itself was not seen as ‘viable’ since it appeared popular and was well attended. Although the group was offered the continued use of a room, and two of the group members attempted to keep the group going, few other women attended and this arrangement was abandoned.

<sup>88</sup> This is not to suggest that their own perceptions of their lives were not important or ‘valid’. I would suggest that the primary reason for respondents not ‘seeing’ constraints was that they did not necessarily

basis that respondents had not reported a lack of choice, or because their concept of independence was relatively limited, would have meant omitting important issues.

Whilst I have tried to separate quotes from analysis and interpretation in the thesis, to make a distinction between what respondents said, and how I analysed this, this separation is artificial. For example, any transcription of a recorded voice is a 'reading' of that voice: decisions are made by the researcher as to where punctuation is placed, and what text is included. Decisions are also made in relation to how much additional information given: for example, where the interview took place might influence what was said, and body language, pauses and tone of voice might affect the meaning of the transcript or contradict what is being said. Thus, in this research, what respondents said was gauged alongside other factors in the interpretation of the data, and although quotes have been used to give some indication of 'voice', this 'voice' is filtered through me.

Additionally, I chose to change some of the language used by respondents. This was a difficult decision because I was unwilling to change anything on the basis that respondents' language was affected by their impairment. However, most respondents used a regional dialect<sup>89</sup> and also tended (like most people) to jumble their tenses and speak in erratic ways that occasionally made little sense in written form. Quotes used were therefore edited, for example by replacing some regional words with more widely used ones, or changing tenses) to make reading easier without, hopefully, losing the sense of what was being said. At times I also edited words out and ran quotes from different parts of the dialogue together. This technique was most often used with those respondents who frequently answered questions (and probes) with 'yes' and 'no'<sup>90</sup>.

I also had to make decisions about how to include women who said very little, or those who were difficult to understand or who responded with 'yes' and 'no' answers whilst not 'overusing' those who talked for longer or used longer sentences: I had a lot of material from one respondent, partly because she attended the focus group and was involved in two relatively long interviews but partly because she was extremely eloquent

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have the same opportunities and experiences as others. Their viewpoint of the world is constrained by what they 'know'. This is therefore the product of *socialisation*.

<sup>89</sup> For example, using 'bairn' for child, and using 'us' for 'me'.

<sup>90</sup> I only did this where the respondent was obviously talking about the same subject, and tended only to do this with text that was located within one page of transcript.

and had a lot to say. Although this respondent was the most vocal and eloquent, other interviewees were also able to discuss the topics covered in some detail, and therefore relatively rich data was gained from ten of the women. Dorothy, Jane and Anne tended to answer questions less fully, and Liz, Vicky and Suzanne's answers tended to be limited to 'yes' and 'no'. I therefore had to try and include those with 'smaller' voices within the analysis, by running comments together, using exchanges between myself and the respondent, and by including a description of the exchange in my text instead of using an isolated quote.

Additionally I also had to consider how to represent respondents' apparent silence on sexuality. Many had difficulties discussing sexuality. Whilst, as suggested, this might be due to a lack of knowledge or experience of sexuality, the words that women can use to describe sexuality or their bodies in non-clinical or non-derogatory ways are limited (Lees 1993, Millard 1994). Although I have attempted to bring this 'silence' into my discussions, I feel that it might not have been given the prominence it deserves, partly because it is difficult to discuss in depth a finding that has no 'voice'.

There were also difficulties in deciding what data to include where information was 'sensitive'. Two respondents spoke about very 'difficult' experiences. With one I made a conscious decision that despite the respondent's wish that her story was heard, to use very little of what she had said. This was partly because the interview from which this data was drawn had essentially served as an opportunity for this respondent to talk about her experiences of abuse. I felt that the need for this woman to talk about her experiences was perhaps stronger than her desire to be involved in the research. As with all the women who told me the details of their abuse, I avoided using explicit descriptions of this. Although I could see the benefit of others reading about those experiences (these things *do* happen to women who have learning disabilities), I was not comfortable using them – particularly since the aim of the research was to explore how these women constructed sexual meaning<sup>91</sup>.

On a final note, and as I have suggested, I had the power to decide what data to include and what data *not* to include in the final thesis. For example, one respondent,

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<sup>91</sup> Whilst I acknowledge that such experiences might shape these meanings, I do not believe that we need to know these in detail to understand this.

who gave me information on abuse, had also asked me not to use that information as data. Prior to the interview we had agreed that she would not talk about that aspect of her life, but found that once the interview began she could not help but refer to it. We renegotiated the terms of the interview and I agreed to edit out any information she gave me about abuse<sup>92</sup>. Whilst I have acknowledged this respondent's experiences of abuse, I have also left out the details that she gave me. Therefore, in relation to these respondents: the first was giving me very sensitive data, the second was relying on me, someone she did not know particularly well, *not* to talk about particular aspects of her life.

## Conclusion

This chapter has outlined the epistemology and the methods used in the research. I began by discussing the methodological framework and research design, with its emphasis on 'voice'. I discussed sampling and access before focusing on each of the three methods used in the research: focus group, semi-structured interview and participant observation. I explored some of the ethical issues the research presented, focusing more particularly on the issues of consent, confidentiality and anonymity, the researcher role, researching sensitive issues, and withdrawing from the field. I finished by exploring some of the dilemmas involved in the writing-up of this research, returning again to the notion of 'voice'. In the following three chapters I will explore the data that emerged from this process.

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<sup>92</sup> This respondent later suggested that her family had thought that I might be 'benefiting from her misery', not realising that the information she gave me about the abuse would not be used, was not deliberately sought out, and was not the primary focus of the interview. This information dissuaded me from conducting a follow-up interview.

## CHAPTER FOUR

### Institutional Accounts of Sexuality

#### Introduction

Within this thesis sexuality is understood as a social construction. It is ‘produced’ or ‘learnt’ via the accounts of sexuality people encounter within everyday interaction with significant others. In turn these accounts reflect and reinforce wider normative discourses of sexuality, including those relating to learning disability and gender. Such accounts and discourses, and the practices that reflect these, act to regulate the sexuality of women with learning disabilities in specific ways. In this chapter I will describe respondents’ perceptions of institutional accounts<sup>93</sup> of sexuality in relation to learning disability, and the wider meanings associated with sexuality in these settings. I will focus primarily on family and service settings, although I will also briefly refer to how respondents developed understandings of sexuality within school and college settings, and through the ‘doing’ of sexuality and relationships. I will also include some of my own observations in relation to the *Sex, Love and Relationships* course, in order to provide additional information on one of the contexts within which over half of the respondents learnt about sexuality. The service settings discussed are examined in terms of the way in which they provide ‘formal’ education on sexuality – for example the *Sex, Love and Relationships* course, as well as in terms of the way in which sexuality is addressed ‘informally’, for example during everyday encounters between respondents and family or service staff.

Underpinning this discussion is the notion that what might be described as ‘education’ (the ‘how to’ of sex, such as descriptions of sexual activity, pregnancy, and how to avoid sexually transmitted diseases), is implicitly and explicitly interwoven with the values and attitudes of those who are providing this. Although the ‘how to’ can be

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<sup>93</sup> It is important to note that all of the interview respondents had significant experience of formal social service provision (e.g. lived in residential services or attended day services) and/or had participated in activities specifically for people labelled as having learning disabilities (e.g. attending college courses, night clubs or the organisation where the women’s group met). It was not possible to ascertain the exact institutional experiences of those focus group participants and *Sex, Love and Relationships* course participants, although it was clear that most had had experience of formal institutional contexts.

analytically separated from values and attitudes, in reality they are not easily disentangled. Thus, the accounts of sexuality within what is seen as ‘education’ or ‘information’ are never ‘value free’.

I will begin by looking at respondents’ reports of family accounts of sexuality. Many respondents felt that their families did not talk to, or educate, them about sexuality, and I argue that this might have had important effects. However, I will go on to highlight the ways in which respondents’ reports suggested that families did in fact talk about sexuality, giving sexuality particular meanings. This was evident in the way in which respondents’ comments showed that they were sometimes constituted as ‘different’ to other family members. It was also shown through the prevalence of ‘normative’ accounts of sexuality and the framing of sexuality as negative. I will then look at service settings, beginning with residential settings. I will suggest that although information and talk about sexuality also appeared to be lacking<sup>94</sup>, accounts of sexuality were nevertheless apparent, for example in the prohibitions placed on some respondents in relation to sexuality. I will then look at the *Sex, Love and Relationships* course, which whilst challenging some of the accounts and discourses reflected in family and other service settings, also reinforced potentially limiting discourses around gendered sexuality.

## Family Accounts of Sexuality

### *Productive Silences*

Two interviewees lived in the family home: one with her mother and siblings, the other with her parents. Another interviewee lived alone, but with relatives living close by. About half had lived with their parents or siblings for relatively long periods of time (for example, beyond the age of twenty-five). Most interviewees appeared to have, or had previously experienced, strong family ties. Most of those who no longer lived with their parents or wider family often spoke of them in ways that reflected their continued influence.

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<sup>94</sup> When using the term ‘lack’ I use it in terms of what respondents *perceived* to be lacking.

Most respondents suggested that parents and/or siblings did not talk to them, or teach them about, sexuality<sup>95</sup>. The following examples were typical of the brief and abrupt responses to my questions in relation this:

*Elizabeth:* Did they tell you anything [about sex], your parents?  
*Jean:* No, no.  
 Jean (66) **I**<sup>296</sup>

*Elizabeth:* Did your parents ever talk to you about relationships?  
*Mary:* No.  
*Elizabeth:* Or sex, or that kind of thing?  
*Mary:* No.  
 Mary (78) **I**

In relation to educating their children about sexuality, previous studies suggest that the parents of people with learning disabilities are cautious about their children learning about sexuality (Craft 1983, Aunos and Feldman 2002). Aunos and Feldman's (2002) study of the empirical research literature relating to sexuality, sterilization, marriage and parenting of people with learning disabilities published in English and French from the 1970s, showed that 'many parents of children with intellectual disabilities held ambivalent or restrictive attitudes and avoided talking about sex with their children' (2002:287), although interestingly, girls received more information than boys<sup>97</sup>, although no suggestions as to why that might be the case were given. Similarly, the Government's Department of Education and Employment publication, 'Sex and Relationship Guidance' (2000:14) for example, states that the parents of children with special needs might be more likely to have problems with their children learning about sexuality in schools than the parents of non-disabled children (both boys and girls), although they fail to give reasons for this. Whilst the parents of non-disabled children

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<sup>95</sup> This is not to suggest that family members will necessarily hold the same opinions on sexuality. It is also important to note that family members are both gendered and sexualised, and subject to normalising discourses too. The term 'family' is not therefore a neutral term (Carabine 1996b, Jackson 1997, 2007). Further, 'family' is not necessarily a concept that is agreed upon. For the purposes of this research I use 'family' as a relatively coherent institutional concept, and in relation to people that respondents class as their own 'family', such as parents and siblings.

<sup>96</sup> I have coded quotes with the name and age (in brackets) of the respondent, as well as the source (in bold). **FG** denotes the focus group, **I** denotes a first interview, and **I**<sup>2</sup> denotes a second interview.

<sup>97</sup> The kind of information was not specified. It is important to note that more information might not mean more 'positive' information.



might also find it 'difficult' to educate their children about sexuality, there is a sense within the literature that this difficulty is greater with those who have children with learning disabilities.

As suggested, not talking about sex can, paradoxically, say a lot about it; particularly that it is something that cannot or should not be talked about (Foucault 1990, Sedgwick, 1990). However, whilst respondents perceived a 'silence' on sexuality (as I have argued, a 'productive' one), the data suggested that family accounts of sexuality, whilst not necessarily focusing on the 'how to' of sex, did however include references to sexuality.

### *Sexuality and Learning Disability: Being 'Different'*

One of the most striking aspects of interviewees' lives as they reported them was the way in which they were marked as 'different' within family settings. Katherine, for example, described being brought up by her grandmother, away from her siblings, who remained with her parents. Katherine frequently referred to the way in which her sisters had grown up differently from her, appearing more confident and 'worldly-wise'. Katherine described her grandmother as working hard to keep Katherine away from boys, as shown in the following examples:

*My grandma, she kept me away from boys...she had a lot of Victorian values.*  
Katherine (54) I

*I think it was because she knew I had a slight learning difficulty, and she knew I was easily influenced.* Katherine (54) I<sup>2</sup>

Whilst Katherine's grandmother might have held particular generational attitudes towards sexuality and gender that would have been applied to Katherine's sisters had they lived with their grandmother too, Katherine also seemed to think that her 'learning difficulty' label influenced the way her grandmother treated her. Katherine's grandmother seemed to be protecting her from 'boys' (who might take advantage of her perhaps), and also warned Katherine that since she had 'problems', she might not find

‘someone to love’ (thus attempting to protect her emotionally). Although most women did not necessarily link their differential treatment to their learning disability, or ‘difficulty’ as Katherine describes it, this sense of difference and the need for protection in relation to learning disability and more importantly sexuality was still evident. Heyman and Huckle (1995) have highlighted the way in which the parents of adults with learning disabilities might fear for the sexual safety of their children (or in this example, grandparents/grandchildren). Scior (2003) highlights the intersection between such a ‘protectionist discourse’ associated with people who have learning disabilities, and gender, and argues that this discourse works to constrain women, particularly in relation to reproductive control. Further, generational differences in parental (or grandparental) opinion were not necessarily apparent in this study, as will be seen in the case of twenty-five year old Julia who will be focused on later in the chapter.

Five of the eleven interviewees aged over thirty reported having lived at home until one or both of their parents died, and Jane, at thirty-nine, still lived with hers. For some women this raised particular issues. Deborah, for example, lived in the family home until her mother’s death<sup>98</sup>, and particularly highlighted the way in which her mother cast her in the role of child throughout this period, as seen in the following statements:

*My mum used to treat me like a baby...she used to talk for me.* Deborah (46) **I**

*She used to be the boss over me though...like she used to do everything for me.*  
Deborah (46) **I**

*Elizabeth:*     *How did you feel about that?*

*Deborah:*     *Well, I felt bad-tempered...Hey, I’m sorry but I’m old enough to talk to people on my own.*

Deborah (46) **I**

The first comment illustrates the way in which Deborah *knew* that she was being treated like ‘a baby’, or at least *felt* this to be so, a concept she then unpacks, suggesting how this meant that she was not allowed to talk for herself, make her own decisions (her

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<sup>98</sup> Deborah’s mother died when Deborah was in her early forties.

mother was ‘boss’), and that she was not allowed to do anything for herself. For whatever reasons (fear or protection?) her mother treated Deborah in a way she experienced as constraint, representing a strong degree of unwanted control, as seen in the third statement. Her mother’s positioning as ‘boss’ clearly undermined Deborah’s adult status, as Deborah highlighted by suggesting that she was ‘old’ enough to talk to people without her mother’s intervention. It might be argued that in her mother’s positioning of her as a child, Deborah was also ‘denied’ a sexuality, since children are routinely cast in terms of sexual purity and innocence (Hockey and James, 2003, Thomson 2004, Renold, 2005), whilst adulthood usually signifies sexual maturity. As previously suggested, disability and learning disability has been linked to a child-like status and asexual status.

Another way in which some of the interviewees were marked as ‘different’ was in the way that family members explicitly told them that having a boyfriend, having sex, having a husband, or having children were things that they could not or should not have. With regards to having a boyfriend Mary reported the following:

Mary: *Oh, my mum and dad didn’t approve of me having a boyfriend, when they were alive [they died when Mary was in her mid-forties].*  
 Elizabeth: *Do you know why?*  
 Mary: *I don’t know.*  
 Elizabeth: *Because they were okay with your sisters, from what you’ve said.*  
 Mary: *Ah hmm.*  
 Mary (78) I

Tellingly, Mary was not saying that her parents were opposed to her having a *particular* boyfriend, or having sex with a boyfriend, as might be expected for other women of her generation: Mary was being discouraged from having any boyfriend at all. As with many of the women in relation to sexual relationships more generally, Mary could not clarify why exactly she was unable to have a boyfriend. Mary’s sisters and brother had boyfriends and girlfriends and got married, suggesting that her parents might have disapproved of her *specifically* out of all her siblings, of having relationships. Whilst the reasons why Mary might have been discouraged from having a boyfriend remain

unclear, Mary does appear to have received differential treatment, marked as ‘other’, and remained at home long after her siblings had left.

Whilst Mary’s parents ‘disapproved’ of her having a boyfriend, Deborah was directly told by both her mother that she *could not* have a boyfriend, get married or have children, as evidenced in the following exchanges:

Deborah:     *My mum used to say I can’t do things.*  
Elizabeth:    *What kinds of things?*  
Deborah:     *Like the kind of thing you’re asking.*  
Elizabeth:    *Like having a boyfriend, getting married?*  
Deborah:     *Yeah.*  
Deborah (46) I

Deborah:     *Well she’d say to me that I’m not old enough, but I am now.*  
Elizabeth:    *So did she say that when you were older as well?*  
Deborah:     *Yes.*  
Elizabeth:    *What reason did she give then?*  
Deborah:     *She said ‘Deborah, you can’t get married.’*  
Deborah (46) I

It is interesting here that Deborah suggested that her mother’s reason for Deborah not having a relationship was her age<sup>99</sup>. However, when she got older it appears, at least in this statement, that her mother avoided giving a reason why she should not have a relationship, simply stating ‘Deborah, you can’t get married.’ This represents a ‘silence’ that nevertheless suggests that for some reason (learning disability?<sup>100</sup>), Deborah is marked as unable to have the same relationships as others. It is also interesting that at various points during the interview, the reason Deborah herself gave for her not being able to get married, was because she was physically impaired. Although this reason is not specifically linked to having a *learning* disability, she has still marked herself as impaired ‘other’, and has connected the prohibition on relationships with this difference.

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<sup>99</sup> Although Deborah did not say at what age this was said, she indicated that it was when she was an adult.

<sup>100</sup> Todd and Shearn (1997) suggest that parents ‘shield’ their children from the label ‘learning disability’ because of the stigma associated with it, and Craig *et al.* (2002) argue that professional staff do likewise. This might explain why, in this study, some respondents were not given reasons for the prohibitions they reported experiencing.

Hockey and James (2003:176) suggest that: ““Growing up” entails the movement towards the achievement of independent personhood, a transition mapped onto the move from “child” to “adult” status, from being someone’s child to having the potential to bear children of ones’ own.’ They further argue that whilst employment is a signifier of adulthood, ‘...motherhood contributes significantly to a mature feminine identity’ (2003:149). It is therefore significant that only two interviewees had children. Four were directly told that they could not have them. For example, twenty-five year old Julia commented, ‘I’m not allowed kids’, and said that her parents gave her no specific reasons for this. Again there is a ‘silence’ here, suggesting that Julia’s parents see her as ‘different’ to others, whilst avoiding telling her why.

Other interviewees reported that they *were* however given reasons why they could not have children, or should not, and many, whilst not being directly prohibited, were dissuaded from having children. This was usually related to interviewees’ ability, or apparent lack of ability, to cope<sup>101</sup>.

*Well my mother says I can’t look after them. She told me I can’t have kids, I can’t look after myself. I know how to look after myself! I’ve lived on my own...I can look after myself! Michelle (29) I*

As Booth and Booth (1994) and Tymchuk and Andron (1994) highlight, assumptions are often made in relation to the capability of people with learning disabilities to parent. Scior (2003) argues that women who have learning disabilities in particular, have their parenting role questioned. Learning disability is explicitly linked to the notion of capability, as I have argued earlier. Despite this, Michelle rejected the notion that she could not cope, and went on to tell me of occasions when she’s acted as a babysitter for her family as proof that she knew how to handle children. A small number of the other interviewees told me about how they too baby-sat for relatives and were well able to do so. Two of the other interviewees also had their *own* children. These challenges were unusual: none of the interviewees argued against parental prohibitions in relation to having boyfriends or in relation to them getting married. This suggests that interviewees

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<sup>101</sup> The assumed inability of people with learning disabilities to cope with parenthood is challenged by Booth and Booth’s (1994) research.

felt particularly strongly about having children, or perhaps they felt that having children was an important aspect of adulthood or 'womanhood'. Further, around half of interviewees who had not had children reported having wanted them at some point in their lives. This desire was expressed more frequently than one for relationships or marriage.

Although two interviewees were told that they should not or could not have a relationship, get married *or* have children, some, like Michelle, were 'denied' the possibility of having children but not the possibility of having relationships. May and Simpson (2003) highlight the way in which until the 1960s and 1970s, people with learning disabilities were dissuaded from marriage, and that this was because it was equated with parenthood. During the 1970s, with the greater availability of contraception, a form of 'companionate marriage' was advocated (2003:33), where procreation, or even sex, was not a feature. May and Simpson suggest that the right of people who have learning disabilities to parenthood has only been acknowledged in the last ten to fifteen years. This acceptance of particular aspects of sex and relationships is reflected perhaps in this study, although an acceptance of parenthood by family members appears to be limited. Aunos and Feldman (2002) found that the majority of the parents described in their own study of the research literature were against marriage, even where their (adult) child used contraception<sup>102</sup>. This suggests that change might be slow.

It is important to note however, that most interviewees had never been told *directly* by their parents or families that they could not have a 'normal' sexual life. In Jean's exceptional case, her mother appeared to imply that she could become a mother, without referring to this possibility directly. Jean reported the following:

*She picked this book up and she cut this part out. It was about a woman that had epilepsy. And she had a little girl...Because I always used to say to my mum, after she got that bit of paper, I'd love a child. Jean (66) I*

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<sup>102</sup> Gender was not referred to, and no reason was given for these opinions.

Jean had physical impairments as a child and had epilepsy throughout her life, so being shown this article was significant to her. Although Jean did not suggest that she was encouraged to have relationships (and reported finding it difficult as a young woman to get out to socialise), and did not report being directly encouraged to have a family, this indirect suggestion that it was acceptable to be disabled and be a mother is important. Jean mentioned this action by her mother more than once, and it appeared to have made a strong impression on her. However, few women reported such positive encouragement to live what might be considered a 'normal' life, and such 'normal' lives were portrayed for most interviewees in normative terms that linked sexuality to marriage and parenthood as I will go on to discuss.

### *Marriage and Children: Normative Accounts of Sexuality*

Much of what interviewees reported families to have said showed that these families held normative views of sexual life that explicitly linked sexuality with marriage and having children. This was reported by interviewees across the age range, as evidenced in the following examples:

*My mum says 'you've got to be married before you have kids.'* Michelle (29) **I**

*It's thanks to my grandma really, she explained what it was about, why you had these things; 'it's because you're becoming a woman. Your body's changed so that you can start to produce eggs and if you meet a boy, if you meet someone and get married and then he can pass on his seed.'* Katherine (54) **I**

Michelle's mother directly links having children with being married. Katherine's grandmother more implicitly links becoming a woman and having the bodily ability to have children with meeting someone, getting married and procreating. In relation to Michelle's comments it might be assumed that generational differences might have been reflected in what her mother told her: although many people do get married before having children, this trend is changing (Haste 1994, Richardson 2000).

Other comments by interviewees about what their parents had told them in relation to sex and marriage reflected gendered perspectives, again irrespective of

respondents' ages and the generational differences this might reflect. For example, the following respondents reported their parents' saying:

*'Save yourself, don't give in too easily.'* Katherine (54) I

*'Don't let anybody touch you.'* Vicky (28) I

Although these comments do not explicitly refer to male or female sexual partners, they are nevertheless reflective of gendered discourses in relation to sexuality. Katherine's mother seems to be suggesting that Katherine should wait to have sex with the 'right person', and probably for marriage, but also that she should not 'give in' too easily. Katherine's grandmother also referred to how 'good girls' behaved in particular ways: 'good girls don't give in on the first date', also suggesting that a woman's involvement in sexual activity is related to 'good and bad', and to 'submission' and 'passivity'.

Vicky's parents similarly cast her in a 'passive' role – she might be 'touched', but not the 'toucher' – and portrayed touch in prohibitive terms. It can be argued perhaps that these learning experiences are not restricted to the lives of women with learning disabilities. It might be further argued that these comments suggested that these women's families were preparing them for a sexual life: although Katherine is being warned not to 'give in', she is not being told she cannot have sex, or that she cannot have sex before marriage. However, such accounts of sexuality are highly regulating, and in Vicky's case at least, as a young woman from a younger generation, relatively unexpected. It is therefore possible that these normative frameworks of sexuality were applied to these women *because* of their 'learning disability label', and that they might act to dissuade them from exploring sexuality. This gendered sexuality, framed within particular normative forms of sexual life, serve to regulate and constrain. By presenting sex within narrow terms, the alternatives available, including the possibility of same-sex relationships, having short-term relationships, or of having a sex life that is not dependent on having a relationship at all, are obscured. Whilst I focused earlier on the ways in which sex, marriage, and/or parenthood were constituted by families as something that some respondents should not, or could not have, these normative sexual



discourses introduce a value to sexual acts that might act in a more subtle way of disciplining respondents in relation to sex. These discourses were accompanied by a strong narrative that frequently presented sexuality in negative terms; as something 'dirty', 'disgraceful' and 'unsafe'.

### *Framing Sexuality as 'Negative'*

Cuskelly and Bryde's (2004) research has shown that parents in particular can feel negatively about the sexuality of their adult sons and daughters with learning disabilities. As well as sex being depicted by family members in normative terms related to marriage and having children in my own study, it was also often spoken of in terms that categorised it as 'dirty' and 'shameful'. Deborah, for instance, reported that when she had once said something about sex to her mother, she had been told not to talk about 'dirty things'. It is interesting that when I asked Deborah if she had been told anything about sex by her parents she said 'no', and yet being told that sex is 'dirty' sends a very powerful message about what it is and what it is not. Katherine's recollections of what her grandmother had said suggested that her grandmother also made a connection between sex and 'shame' or 'dirt': Katherine reported that her grandmother had said that 'the act itself is nothing to be ashamed of', yet she is also suggesting, by her use of the word 'ashamed', that it might be. Katherine commented on this, saying 'a lot of grandmas would say it was dirty, you haven't got to talk about it.' In the following example, Jean related how her family might consider her watching sex on television to be a 'disgrace':

Jean: *It's getting worse that [the television], for things like that [sex].*  
Elizabeth: *Why would you say it was worse? What makes it worse?*  
Jean: *I don't know, really. Even if there was a film on I would, if there was sex in I would, I think I would just turn it over. I think in case my family comes and asks 'what are you watching this for, it's a disgrace?' Because that's what my family are like.*

Jean (66) I<sup>2</sup>

These examples show how strongly sex can be related to in negative terms; it is something to be ashamed of, and it is also something that we should not talk about (because it is so ‘bad’). Interestingly, Jean’s comments show that her family’s opinions in relation to sexuality are influential on Jean’s actions. Foucault (1990) describes the way in which we are self-disciplining; we are not only coerced into acting in certain ways by direct means, but also in indirect ways which rely on us disciplining ourselves. Here Jean is still governed by her family’s opinions (which are in turn governed by wider discourses), even though they are not physically with her. Again, whilst there is no explicit link between families relating sex with dirt/disgrace/shame and the prohibitions in relation to sexuality reported by respondents on the basis that they have a learning disability, the degree to which these negative aspects of sexuality are represented within the data suggest that there might be one. Further, I would like to suggest that this focus on sex as dirty/disgraceful/shameful, might be linked to gender on the basis that sex and gender have been linked to what is ‘good’ and ‘bad’, as suggested in the previous section. Women, for example, are more likely to be censured for enjoying sex than men (Lees 1993, 1997).

Sex was also explicitly linked to safety by some of the interviewees’ families. As already discussed, I would suggest that there was a strong element of protectionism involved in the ways in which families presented sexuality. Sexuality is entangled with notions of risk and safety in general discourse (Tepper 2000), especially within the context of HIV and AIDS. Further, the notion of risk is also strongly linked to discourses around learning disability, with its construction based on ‘ability’, and more particularly in relation to learning disability and sexuality (Rose and Jones 1994). As suggested earlier, Katherine’s grandmother had, in Katherine’s words, ‘mollycoddled’ her, possibly on the basis that she had an intellectual impairment and/or had been labelled as having a learning disability. She had also been brought up differently to her sisters who had what she described as more ‘freedom’. Katherine gave the following examples of how her family tried to help her ‘stay safe’:

*She [Katherine’s grandmother] tried to keep me as safe as she could, knowing what to expect from boys. Katherine (54) I*

Being safe appeared to involve knowing what to ‘expect’ from ‘boys’ (boys were ‘different’ to girls), but also included using condoms. This latter focus was unusual in relation to the data more generally, and showed that Katherine was seen as someone who might (and could) engage in sexual activity. However, this sexual activity was seen within a wider discourse of safety, where she needed to know what to expect from boys to keep ‘safe’. Although it was not clear what ‘safe’ might mean specifically, sexuality (and pregnancy) was frequently discussed by interviewees in terms of risk rather than enjoyment. This general stress on safety, although perhaps necessary (Alaszewski and Alaszewski 2005, Brown and Scott 2005), is often a ‘negative’ discourse, suggesting that either women who have learning disabilities and/or women in general are at risk sexually – physically, and perhaps, emotionally. As Scott and Jackson (1996) have highlighted, a tension exists between pleasure and danger in relation to sex, particularly in relation to women.

It is clear that interviewees, despite some suggesting that their families told them very little about sexuality, learnt a great deal about what it meant (for example that it is linked to marriage and parenthood), that it ‘was not for them’, and that it could be ‘dirty’ or unsafe.

## **Sexual or Intimate Relationships**

Three interviewees explicitly referred to learning about sexuality from having sexual relationships or encounters<sup>103</sup>. These references included:

*I know about sex, I had it before.* Jeanette (50s) **I**

*I’ve learnt more from the one [boyfriend] I went with [than being at school], I learnt more.* Michelle (29) **I**

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<sup>103</sup> Interestingly however it was only the male members of the *Sex, Love and Relationships* course that mentioned learning about sex by ‘doing’ sex (in comparison to the female course participants, who did not mention this).

These comments were in response to a question in relation to where and how respondents learnt about sex, and highlight the importance of learning about sex and relationships by the 'doing' of sex and relationships. Jeanette's first reference in relation to where she had learnt about sex was to the fact that she had 'had it before', suggesting that this experience was significant in the development of her knowledge of it. Michelle suggested that she had learnt more from a sexual relationship than she did at school, again highlighting the importance of experience.

McCarthy (1999) has highlighted how her own respondents felt that they learnt about sexuality by the 'doing' of it, and how sexually abusive experiences were particularly referred to in relation to this. Seven out of the ten interviewees in my own study, who reported experiencing sex or having relationships, spoke negatively about them<sup>104</sup>. Some interviewees, for example, learnt that sexual relationships could be violent and exploitative: of the four interviewees who had been or were married for example, three had experienced physical violence. Charlotte, for example, learnt that her husband could hold more power than she could by using his knowledge of her likes and dislikes against her. Charlotte's husband would coerce her into sleeping with friends and neighbours in this way:

*Because the [pension] book was in his name, he signed it, he held the money, he paid the way...He would get what he liked, and I liked cheese, I liked yoghurts, I liked fruit and he knew exactly what I liked, and if I didn't do that to please him he knew exactly how to get me back, you know, 'right you're not getting this, you're not getting that. Charlotte (56) I*

*He used to fetch my past up...that was so unfair, he knew that when I was at home I was interfered with by my brother. Charlotte (56) I*

This manipulation was directly linked by Charlotte to her intellectual impairment, as well as the way in which she had been labelled as having a learning disability. In this instance Charlotte's husband was wielding financial control over her, as well as his knowledge of what she desired, and coercing her into the passive role associated with

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<sup>104</sup> It is important to note however that all those in relationships at the time of interview spoke positively about them.

both gender and learning disability (Oliver 1990, Morris 1993b). Perhaps more disturbingly, but also relevant to the discussions here, is the way in which he used his knowledge of her sexual past against her. Wellings *et al.* (1994) (whose UK research, conducted over eight years with surveys of 18,876 men and women aged sixteen to fifty-nine, and is described by the authors as ‘a study of late twentieth century lifestyles’) have shown that the ‘double standard’ that reflects that women have less sexual ‘leeway’ than men is still in place, despite increasingly liberal attitudes towards sex. Other work has also discussed this, for example Hollway 1984, Walby 1990, Lees 1993, 1997 and Richardson 1997. These experiences highlight the way in which women bear the burden of (male) sexuality (Lees 1993). In her ethnographic study of children attending primary school in the UK, Renold (2005) found that this gendered sexual responsibility is carried by girls as young as eleven. In relation to being abused by her brother, Charlotte was disbelieved and sent from home, compounding the sense that she was responsible for what her brother had done.

This sense of sexual responsibility was also experienced by Michelle. Michelle was described as a ‘slut’ by her father for having a relationship with someone who had a girlfriend, as evidenced in the following quote:

*My mum said my dad kept calling me a slut, and everything. ‘Cause he [her boyfriend] was going out with some other lass at the time. And he was sleeping with both of us. And I got a reputation. Being called one of them. Michelle (29) I*

Lees (1993, 1997) has highlighted the way in which young women are labelled ‘slags’ for showing an interest in sex. Although such comments, though gendered, might therefore apply to non-disabled women, it nevertheless compounds the sense that sexuality is ‘not for’ Michelle, a woman labelled as having a learning disability.

As suggested earlier, Charlotte felt that her husband had treated her in particularly violent and manipulative ways on the basis of her impairment and learning disability label. Similarly, Katherine, whose husband was physically violent, stated that she had been targeted for being ‘vulnerable’ but that, more positively, she had learnt from this:

*He [Katherine's husband] saw that I was vulnerable, and he saw that I was easily controlled, easily persuaded. He thought I would be someone who would just automatically do what he wanted. Katherine (54) I<sup>2</sup>*

*But I wouldn't be as naïve as I was, having experienced this. I wouldn't be as naïve, I would know what to look out for now and you know, I would know if the relationship was worth pursuing. Katherine (54) I<sup>2</sup>*

It is interesting that whilst Katherine makes a link between vulnerability, and the way in which being overprotected can compound this, she also uses the words 'he thought I would be someone who would just automatically do what he wanted.' This suggests that she thought that she might *not* be someone who would do what her husband wanted. By experiencing a 'bad' relationship, she was capable of learning how things might be different, that her impairment might not stop her from learning that things can be otherwise, thus challenging her socially constructed vulnerability.

Whilst most respondents who had been married discussed this experience in negative terms, Liz expressed positive feelings about hers. Although I found her difficult to understand, Liz conveyed her feelings for her husband by asking me to get a photograph album from a shelf, which she opened to show a picture of herself and her husband on their wedding day. Stroking his picture with her finger affectionately, she said 'my husband, my husband.' Throughout the interview, despite my limited understanding of some of her comments, it was clear that she felt positively about him. Jane's comments too show that she had learnt about the positive emotions relationships can bring – whilst not married she was in what appeared to be a stable relationship. This is evidenced in the following exchanges:

*Elizabeth: So, how did you meet your boyfriend?*  
*Jane: He works in [names sheltered employer].*  
*Elizabeth: Right, so you met him at work?*  
*Jane: Yes. 'Cause I fell in love with him.*  
*Elizabeth: Why did you fall in love with him?*  
*Jane: I fancied him.*  
*Elizabeth: What made you fancy him?*  
*Jane: Being romantic.*  
*Elizabeth: He's romantic?*  
*Jane: Yes.*  
Jane (39) I

It is clear that respondents, like other women, had experienced positive and negative aspects of being in a relationship, thus learning about particular kinds of sexuality, relationships and emotions. However, two respondents directly linked their *negative* experiences to having been categorised as having a learning disability and/or as having an intellectual impairment, and positive experiences were described by a minority. I would now like to move on and look at the role of formal settings in relation to sexual accounts, starting with an exploration of staffed residential settings.

## Accounts in Service Settings

### *Staffed Residential Settings*

Of the fourteen interviewees who reported receiving staff support in their homes, eight interviewees lived in residential service or supported living-style accommodation, one lived in a ‘family placement’, and one lived with her husband – all with twenty-four hour support. Three lived alone but with regular staff support at particular times of the day or week, and another lived with a family member, also with additional regular staff support.

Table 4: Breakdown of interviewees by living arrangement

|  |   |
|--|---|
| Small group home (up to six householders)      | 7 |
| Residential home (seven householders or above) | 1 |
| Family placement                               | 1 |
| With partner, 24 hour staff support            | 1 |
| Lived alone, with regular staff support        | 3 |
| Lived with mother, with regular staff support  | 1 |

Research has shown that staff can be highly influential on service users’ lives (Robbins 1990, McCarthy 1999, Murray *et al.* 1999, Johnson *et al.* 2002). Respondents’

comments tended to suggest that members of staff were not significant sources of sexual information or support in relation to sexuality, reinforcing similar findings in McCarthy's (1999) study. In relation to sex and relationships, some respondents suggested that they would actively avoid discussions about sex with staff, or would not talk to them if they needed advice. Liz for example, who was married and had carers working and sleeping in her home, said that she would not be able to ask staff for advice on things like condoms.

Others felt that staff might be approached with reservation. For example Dorothy said that she felt she could approach staff 'a little bit, but not much' and whilst Susan had told the staff who worked with her about being sexually attacked much earlier in her life, she was also concerned that they did not find out about what she had told me during her interviews. Sally too suggested the following:

*Sally: I would tell them [staff] some things but not other things.*  
*Elizabeth: What things might you talk about?*  
*Sally: Well I wouldn't be, I wouldn't be comfortable to tell them that I did it. But other stuff I will.*  
*Elizabeth: So you mean if you had sex?*  
*Sally: Yeah*  
Sally (25) I

Although most respondents did not give explicit reasons why they did not speak to staff about sexuality, their responses suggested that this was because sexuality was a 'difficult' and embarrassing subject. This was supported by the way in which those respondents who reported talking to staff about sexuality avoided 'explicit' subjects. Although such subjects are sometimes difficult for anybody, including non-disabled people, to discuss, professional staff play a central role in relation to supporting people with learning disabilities in all aspects, including the sexual and emotional aspects, of their lives. As the Department of Health (2001a:81) has highlighted: 'Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature.' I would suggest that in order for this to happen, both staff and service users need to feel relatively comfortable with each other when talking about sex. Katherine, for instance, suggested that it might be useful to be able to talk to care staff about particular things:



*I think if you had a problem and you did have someone you could confide in with it'd be a good thing. Like a key-worker<sup>105</sup> or counsellor or a social worker or something. Katherine (54) FG*

Although I would not suggest that staff needed to be considered the friends of service users in order to support them in relation to sexuality, and whilst I recognise there might be difficulties in maintaining a professional role if friendship becomes a part of that role, I would argue that if service users consider staff as friends, or to be like friends, it might be more likely that the sensitive subject of sexuality is addressed. Although I did not ask all the respondents whether they considered staff members to be friends, those I did ask said 'no' (although Anne described her carer as the person she was 'closest' to<sup>106</sup>). Generally, however, staff were clearly demarcated as 'professionals'.

Other barriers to talking about sexuality were also evident. Most of those interviewees living alone (three out of four) did have staff support on a regular basis, as well as contact with social workers, but this kind of contact had less potential to provide them with emotional support, mainly because of the level and type of support received (for short periods of time and for specific and usually practical tasks like help with shopping or housework). Additionally, the availability of social workers was not guaranteed. As Michelle pointed out, she found it difficult to get in touch with her key-worker when she wanted to talk about a relationship that she was having problems with, as evidenced in this comment:

*I phoned [key-worker] and he just was never there. Michelle (29) I*

The overall impression that I gained from the data was that respondents did not necessarily find talking to staff about sex or relationships easy, or that staff approached respondents to talk about these, making this a 'silence' that suggested that sexuality was a 'difficult' subject. This 'silence' was particularly significant as few of them talked

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<sup>105</sup> A key-worker is a paid professional who is directly responsible for ensuring that a service-user's needs are met on a day-to-day basis.

<sup>106</sup> This might have been because she was a live-in carer that she had shared her home with for ten years.

about these matters with anyone else, including (perhaps unlike non-disabled people) their friends. However, despite this silence in relation to respondents' own sexuality, other people's sexuality was sometimes discussed with staff. For example, Vicky reported that in her home, staff would talk about their personal lives, and Sally suggested that she discussed other people's relationships with her carers:

*...like rumours that I heard, gossip. Sally (25) I*

This suggests that sexuality might be a relatively comfortable topic if it was 'distanced', and about somebody else. This has the potential to underline the notion that sexuality is something that happens 'out there' and is not a part of, or likely to be a part of, respondents' personal experience.

In the previous section I suggested that family accounts of sexuality underlined the kinds of discourses that render people, and particularly women with learning disabilities, as sexually 'unintelligible'. This was reflected only twice explicitly in respondent's accounts in relation to residential services. For example, Julia perceived that she was directly prohibited from having relationships whilst living in her (residential) home. Interestingly this prohibition was not gendered, but applied to all the people living with her:

*Elizabeth: You live with two men, do they have girlfriends?*  
*Julia: No, they're not allowed.*  
*Elizabeth: Who said that?*  
*Julia: I don't know, staff said.*  
*Elizabeth: So the staff had said to all of you –*  
*Julia: We're not allowed.*  
Julia (25) I<sup>2</sup>

Whilst it is unclear whether staff in Julia's home actually said this, the fact that Julia *perceives* this to be so is her 'reality', she *believes* that she cannot have a relationship, which is as limiting as if it were the case. As Craft and Brown (1994) have noted, service staff are strongly influential on the way in which service users perceive the world, and research has suggested that some people with learning disabilities are unsure of their sexual rights, including their right to have a relationship at all (O'Callaghan and

Murphy 2007<sup>107</sup>). In this study, Julia's perceived prohibition extends to her male housemates, and there is therefore a sense that living in this residential environment, an environment which is different to other people's home environments (Julia was aware for example that her siblings were married), 'naturally' brings with it certain (sexual) prohibitions, although these are not necessarily gendered. Julia seemed unsure about why staff, as she perceived it, might be stopping her from having relationships, and this again represents a 'productive silence' where whilst the reasoning behind the prohibition is omitted, the connection between Julia's 'difference' and the apparent impossibility of relationships is made clear.

Julia also reported that she was told that she could not get married, something she knew made her 'different': she had for example commented that her father could get married, whilst she could not. She also felt that she had little control over prohibitions made by staff (and her parents), as seen in the following quotes:

*If staff think I'm getting married I'd get into trouble. Julia (25) I*

|                   |   |
|-------------------|---|
| <i>Elizabeth:</i> | <i>Do you think it's right that people can say you can't have kids?</i>   |
| <i>Julia:</i>     | <i>I don't know.</i>  |
| <i>Elizabeth:</i> | <i>Do you ever feel annoyed with people when they say that?</i>           |
| <i>Julia:</i>     | <i>It's nothing to do with me, it's to do with staff.</i>                 |
| <i>Elizabeth:</i> | <i>You getting married, don't you think that's your decision?</i>         |
| <i>Julia:</i>     | <i>No, it's not.</i>  |
| <i>Elizabeth:</i> | <i>It's not your decision?</i>  |
| <i>Julia:</i>     | <i>I'm not allowed, I was told I was too old.</i>                         |
| <i>Elizabeth:</i> | <i>Too old?</i>   |
| <i>Julia:</i>     | <i>Yes, I'm not allowed.</i>  |
| <i>Elizabeth:</i> | <i>Would you ever consider doing something despite being told not to?</i> |
| <i>Julia:</i>     | <i>No I'm not allowed, I'd be in trouble.</i>                             |
| <i>Elizabeth:</i> | <i>What would 'in trouble' mean though?</i>                               |
| <i>Julia:</i>     | <i>I don't know.</i>  |
| <i>Elizabeth:</i> | <i>Do you know what would happen?</i>                                     |
| <i>Julia:</i>     | <i>I don't know.</i>  |
| <i>Elizabeth:</i> | <i>Would you ever go against what somebody told you to do?</i>            |
| <i>Julia:</i>     | <i>No, I've got to stick to the rules.</i>                                |
| <i>Elizabeth:</i> | <i>You've got to stick to the rules? Who said that?</i>                   |
| <i>Julia:</i>     | <i>Staff.</i>   |

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<sup>107</sup> In research which assessed 120 people with learning disabilities' understanding of the law, in the UK.

*Elizabeth:*     *And are you okay with that?*  
*Julia:*         *I'm not too sure.*  
Julia (25) I<sup>2</sup>

Julia did not seem to think that she could do what *she* wanted or resist in any way. When I asked her if she felt that it might be up to *her* whether or not she got married, Julia replied that it was not, and when I asked her if she would consider doing something that staff had told her not to she replied that she would not and said 'I'd be in trouble.' Julia was not able to tell me what being 'in trouble' might mean or what would happen if she was. She simply said 'I've got to stick to the rules.' When I asked Julia about her feelings in relation to these constraints she said that she did not know; that she was not sure. Traustadóttir and Johnson (2005) have highlighted the way in which people with learning disabilities can 'give in' to others. Goble (1999:456), in relation to his UK interviews with five men and two women with learning disabilities on their perceptions of staff in the services they used, suggests that 'a passive acceptance of external power was characteristic of participants' accounts, even when it impinged on major life decisions.' Harris (2003) further argues that if people cannot relate their actions (i.e. choices) to the things that happen to them they develop the belief that they are powerless and take on passive roles. Julia's suggestion that she might be 'in trouble', if she got married, was echoed in an interview with Anne, who was fifty-five, and yet referred to herself being 'naughty' when she refused to do what her carer asked of her. This suggests not just that these women 'comply' (or not) in relation to the people that work with them, but also react as if they were less than adult. It is interesting that both Anne and Julia see agency as something that might make them 'naughty' or likely to break rules. Scior's (1993) research found that some of her respondents too, were referred to, or referred to themselves, as if they were children within service settings.

It was suggested by another interviewee, Susan, that staff who worked in a larger 'old-style' residential home that she had lived in previously had told her that she could not have a boyfriend. When I asked her about this she replied:

*Well only the staff when I lived at [name of home]. I'm not supposed to have a boyfriend.* Susan (56) I<sup>2</sup>

Susan seemed to think that she was told not to have a boyfriend in order to keep her 'safe'. Susan had been attacked and raped some years earlier and this prohibition (if indeed it was a direct prohibition rather than – as is more likely – a suggestion not to have a boyfriend or even a particular boyfriend<sup>108</sup>) was, perhaps, an attempt to protect Susan, who had a particular fear of sex. As already suggested, attempts at protection however might serve to leave these respondents more vulnerable, and certainly serves to constrain what they can and cannot do. Rather than help Susan to find ways of dealing with what had happened to her in order to help her to move on, have another relationship, and manage risk, this action suggests that staff felt that avoidance of the issue was preferable.

Whilst these reports suggest a prohibitive stance in relation to respondents' sexuality, Jeanette reported an encounter that underlined the way in which sex might take on negative meaning within residential settings. In the following example she describes being sexually attacked by a fellow resident in the hospital institution she had previously lived in<sup>109</sup>:

*Jeanette: I got wrong for it [being raped]. And I got grounded for it.*  
*Elizabeth: You got grounded for it?*  
*Jeanette: Yeah. I did.*  
*Elizabeth: But you were raped.*  
*Jeanette: I was raped.*  
*Elizabeth: Why did you get grounded?*  
*Jeanette: Well (they) told me it was my fault. And he [the attacker] got sent to court for it.*

Jeanette (50s) **I**

*And I got wrong. I got grounded. I couldn't go out. Twenty-four hours... Grounded me. I had to be checked from the doctor. I didn't have a period for six months. And then I went to the general hospital, to the clinic. To get a thing up me. A finger. Make it cleaner. And was cleaned with a sponge. And then I had a coil fitted in. And after that when my periods were heavy, very heavy, I had it put out and had my tubes tied...I felt awful when I had the coil fitted in. I felt uncomfortable.* Jeanette (50s) **I**

<sup>108</sup> In hindsight I would have followed this comment up in order to find out more about it.

<sup>109</sup> Jeanette did not say at what age this happened, but given the contextual information she gave me this experience might have occurred at any time (as an adult) up until the age of around forty.

Clearly, being raped by a fellow resident was influential on Jeanette's subsequent sense of herself in sexual terms, as she decided never to have sex again on leaving the institution where the rape occurred. In relation to the meanings that might be associated with this experience, Jeanette reported that others had suggested that the rape was her 'fault', echoing discourses that suggest that men have difficulty in controlling their sexuality, and that women are responsible for ensuring that this sexuality is curbed (Lees 1993). It also reflects the argument that women must take care not to 'arouse' this uncontrollable sexuality, often seen in relation to the way in which women dress. It is important to note that whilst Jeanette is supposedly at 'fault', she is also 'grounded', suggesting that her autonomy could also be curtailed. Further, the word 'grounded' is often used in relation to teenagers, suggesting that Jeanette related to a less than adult status. Todd and Shearn's research (interviews with the parents of eighteen adult daughters and fifteen adult sons with learning disabilities) showed that parents, whilst constructing their children as childlike, also recognised their offspring had adult qualities, and framed them as adolescent: a 'betwixt and between status' (1997:348).

The events that happened after Jeanette was raped (possibly including an abortion or forced sterilisation given her description), represent further invasive and uncomfortable experiences for her over which she appears to have had no control. Whilst Jeanette later said that it was *her* decision to have a coil fitted, in this passage there is a sense that Jeanette's control of her own body had slipped away from her. This is important to note given that the rape also represents a lack, or loss, of control. Thus the rape (and sexuality) is something that can be Jeanette's 'fault'. This is given further meaning by the actions of those around her, so that the rape, and what follows, becomes something uncomfortable, out of her control, 'dirty' (she needed to be 'cleaned') and 'wrong'.

Women with learning disabilities have clearly had their fertility regulated in the past, particularly during the eugenic period. Recent research suggests that in service settings their use of contraception is controlled (McCarthy 1998a, 1999). Further, Stansfield *et al.*'s (2007) retrospective case note study of all referrals to the UK Official Solicitor's Office between 1988-1999, for the sterilisation of people who lacked the 'capacity' to make this decision, showed that 99% had a learning disability, with 96% of

referrals for women, and with 75% of referrals made by parents (usually the mother). Seventy-five percent of referrals were in relation to single people, who were not considered likely to enter a relationship of any kind, although some (12%) had previously experienced sexual abuse and 27% were minors, aged between twelve and seventeen, at first contact. Additionally, although the majority were classed as between 'moderate to severe/profound' learning disability, 9.5% had 'mild to moderate learning disabilities'. Previous to the 2003 Sex Offences Act, those classed with 'mild' to 'moderate' learning disabilities were not considered to be sexually 'at risk' in relation to the law, in the same way as those classed as having 'severe' learning disabilities (and described as 'defective') (Robbins 1990, Gunn 1991). It is therefore significant that those classed as 'mild' to 'moderate' in Stansfield *et al.*'s study, whilst apparently considered able to give consent to sexual activity, were nevertheless referred for sterilisation. The main reason given by Stansfield *et al.* for referrers requesting sterilisation was the perceived risk of pregnancy, and the authors note that sterilisation does not protect against other 'risks' (such as sexually transmitted infections), thus making 'procreation' and associated parenting the issue. Reasons for not using other contraceptives included the limited awareness of the person for whom sterilisation was requested of contraceptive options, referrers wanting to avoid the use of 'horrible' or harmful injections or drugs, adults' lack of ability, and occasionally because referrers feared that the person's child would be born with an impairment. Seventy-nine percent of applications were approved by the court. The authors of the study state that:

It appears that sterilisation was not being used to enable a positive sexual relationship free from worries of pregnancy, but rather, for fear of the unexpected...We hypothesise that request for sterilisation may be driven by a combination of a fear of the risks associated with the person's transition to adulthood, parental contraceptive attitudes, the requirement for a permanent solution to potential pregnancy and concern about who would care for any grandchild. (2007:577)

This research suggests, unlike the wider population, people, and particularly women, with learning disabilities, continue to experience the procreative control of others over their own bodies.

I will now turn to another formal service setting, the organisation where the women's group met, and the course on sexuality it runs. More than half of the focus group participants and interviewees had attended this course, which represents a challenge to the generally 'negative' discourses around learning disability and sexuality discussed so far.

### *The 'Sex, Love and Relationships' Course*

*Elizabeth: Do you know what condoms are?*

*Deborah: No. Are they for your periods?*

Deborah (46) I

Davies (2000) has highlighted the lack of sex education accorded to disabled people, arguing that 'We have been excluded from most of the dominant socialization processes that help teach and prepare people for love, sex and intimacy.' McCarthy and Thompson have similarly argued, in relation to people with learning disabilities, that knowledge about sex is:

...picked up gradually as we go along, often in the form of euphemisms, jokes and hints and often from written sources. People with learning difficulties are at a great disadvantage in this. They may not be able to read or understand sexual innuendo (although like others, they may feel under pressure to pretend they do) and they may not have anyone to help them make sense of it. (1992:4)

The authors therefore argue that 'formal sex education for people with learning disabilities is clearly more significant than for other adults' (1992:4). This issue was highlighted by Jean, an interviewee, who was a member of the planning team for the *Sex, Love and Relationships* course, and who suggested that the course was important because many of those attending it, including younger participants, lacked knowledge about sex.

Before discussing the *Sex, Love and Relationships* course I will briefly describe the role of school and college, and other formal settings in which sexuality might be



discussed. School was not generally reported by respondents to be a place in which sexuality was talked about. Four of the interviewees, all aged over forty-five, suggested that sexuality was not discussed at all. Others suggested, as one woman described it, that talk focused on ‘the basics’; physiology, pregnancy, and contraception.

Day services and college classes were also referred to by respondents as locations where sexuality was sometimes discussed. No respondents were able to report in detail on their experiences of day services and colleges in relation to sexuality, although both focus group and *Sex, Love and Relationships* course participants listed these as places in which sexuality might be formally learnt about. One interviewee mentioned that hygiene had been taught on one college course, and another mentioned that she had been taught about condoms, and how to use them. Although one interview participant stated that she had learnt about sexuality primarily on one of these college courses, she was unable or unwilling to discuss what this might have included.

These few comments suggest that sexuality was dealt with in terms of physiology, pregnancy, contraception and hygiene (biological aspects) rather than wider issues around negotiating sexuality and relationships, reflecting the kind of information provided in schools. Whilst sex education might be seen to be ‘lacking’ by both respondents and the wider literature (Brown 1983, Heyman and Huckle 1995, Shakespeare *et al.* 1996, Gillespie-Sells *et al.* 1998), it seems that it is particular aspects of sexuality that are in fact ‘missing’: the emotional and social. This focus on the biological gives an account of sexuality that leaves out issues related to gender (despite its focus on male/female anatomy), and how people interact. When Chivers and Mathieson (2000), who developed a training package about sex and relationships for Australian staff working with disabled people, asked disabled Australian men and women about what they wanted to know more about in relation to sex and relationships<sup>110</sup>, respondents answered that they wanted to know how to socialise with potential partners and/or how to ask people out. Thomson (2004) has argued that an emphasis on sexual health in schools limits young people’s ability to become sexual agents. Chivers and Mathieson (2000) suggest further that a limited ‘biological’ focus disconnects intimacy, desire and pleasure, from sex. This lack of focus on the

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<sup>110</sup> The authors did not state how many people they spoke to.

pleasurable aspects of sex represents a ‘missing discourse of pleasure’ (Tepper 2000:283) or ‘missing discourse of desire’ (Fine 1988). Tepper (2000) highlights the way in which a lack of inclusion of pleasure, or desire, in sexual discourses disempowers and constrains disabled people, particularly disabled women, by failing to suggest that they can be sexual agents, capable of sexual pleasure.

In contrast to this, the *Sex, Love and Relationships* course was seen by most respondents attending it as an important source of information on sexuality<sup>111</sup>. Of the sixteen interviewees, nine attended the course, and of the focus group participants, half had attended. With the prior knowledge that many respondents had attended this course<sup>112</sup>, it was deliberately referred to in the focus group and interview schedules. It is important to note that the inclusion of such a course alongside other courses at the centre where the women’s group met (as well as the subject of sexuality on courses within day services and on college courses for people with learning disabilities elsewhere) suggests in itself that people with learning disabilities, particularly those beyond school age, might specifically ‘lack’, or want, particular information on sexuality, or might find it difficult to understand or retain the information that they are given. Why this might be the case was not something that was explored fully in this research (and would have required research with formal organisations in order to do so).

Two of the focus group participants said that they had only ever learnt about sex or relationships on the *Sex, Love and Relationships* course, and Katherine (who had previously been married with some sexual experience) and Jean reported the following:

*...it wasn’t until the ‘Sex, Love and Relationships’ course that I’d seen condoms.*  
Katherine (54) I<sup>2</sup>

*I didn’t know anything about pregnancy, but we had a video and we watched it see. We’ve got one at the organisation where the course is held, and I used to*

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<sup>111</sup> However, not all respondents had attended the course to learn about sex or relationships, or only because of this. Other reasons included being able to get out of the house, being able to spend time with others, or simply because ‘they had been asked’. Similar reasons were also given by those attending the course during my observation of it.

<sup>112</sup> The course facilitator drew my attention to the course early in our relationship, informing me that many of the women attending the women’s group had also attended the course, and that it might therefore be of interest to me.

*watch it. And I watched one about relationships and all this, sex and that. Jean*  
(66) I<sup>113</sup>

For these respondents then, the *Sex, Love and Relationships* course was perceived to be their first chance of finding out about particular aspects of sexuality, usually considered to be ‘common knowledge’. As is evident, the course covered similar ‘biological’ aspects of sexuality that might be taught in schools. These aspects were seen as important, for example the *Sex, Love and Relationships* participants I observed commented in particular about the biological aspects of the course, for example: ‘masturbating’, ‘erections and orgasms’, ‘penises and vaginas’ and ‘condoms’ (see Appendix Twelve).

However, the course went beyond this biological aspect to cover institutional abuse. The following is taken from my observation notes of a role play that initially included two of the course planners (volunteers with learning disabilities<sup>114</sup>), who played ‘John’ and ‘Sarah’, and a female course facilitator who played ‘Sarah’s’ friend.

‘John’ (carer) follows ‘Sarah’ (service user) into day service toilets. He tries to kiss her and touch her. She backs away/says ‘no.’ He says she is a ‘spoilsport’ and leaves. Sarah tells her friend, who with Sarah’s permission, informs the day service manager. He (the day service manager) talks to Sarah, listens to what she has to say and promises to deal with it.

The group splits into two (men/women) to explore ‘what is abuse/sexual abuse?’, ‘what should happen to the carer?’, and ‘how we’d react’, ‘rights’, and ‘who might help?’

One respondent also spoke of a women-only version of the course where they were visited by a woman from the local Rape Crisis Centre. Whilst this kind of course content underlines the risky nature of sex, and perhaps the vulnerable status of people, and more particularly women, with learning disabilities, the *Sex, Love and Relationships* course

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<sup>113</sup> Jean does however contradict this when she reports that her mother gave her a book on pregnancy, and it is worth noting that Katherine had also suggested that her grandmother had shown her condoms at an earlier date. Despite this discrepancy I would suggest that the course made a significant enough impression on both of these women for them to make these comments, and that more information on condoms and pregnancy might have been made available to them than previously.

<sup>114</sup> Although the role plays usually started with the volunteers playing the roles, participants were usually asked to take part as characters once the ‘scenario’ had been established, thus giving them a chance to ‘act out’ these situations and practice how they might behave in them.

also provided its participants with ways of dealing with risky situations, thus also challenging the assumption that people with learning disabilities (and women) are necessarily vulnerable. One *Sex, Love and Relationships* participant I observed stated that knowing that nobody could force him to have sex was an important aspect of the course.

One of the most appreciated aspects of the course was the way in which it made learning fun – particularly with the use of role play, as the following examples illustrate:

*But she [the nurse teaching them about contraception] did it in a fun way, you know.* Katherine (54) **FG**

*Well, you get a bit of a laugh out of it with the role plays and that.* Jean (66) **I<sup>2</sup>**

Role play was consistently cited as an important aspect of the course by interviewees, and participants on the course (as observed during my participant observation) also highlighted it as one of the things about it that they most liked, with comments ranging from ‘quite good’, ‘good and funny’ to ‘excellent’. Whilst role play was considered to be fun, it might also be particularly useful in relation to helping participants gain the confidence to deal with unfamiliar situations, as well as perhaps familiar situations that they previously might not have known how to deal with.

As suggested, a ‘limitation’ of the sex education some respondents reported encountering more generally was its focus on the biological rather than the emotional or social. Whilst the ‘biological’ was deemed important by the participants I observed, other aspects of the course were also highlighted. The importance of feelings was made clear by one male *Sex, Love and Relationships* course participant who said that he felt that the course was important in relation to ‘what we feel and that.’ Also, Katherine, an interviewee, particularly appreciated this aspect of the course:

*Before I came to [the centre] all I knew was the bare facts, you know. How you did it. And what could happen if you didn’t take precautions. But they didn’t tell you about the emotional side. Or the other things that go with it, you know. Whereas the ‘Sex, Love and Relationships’ course does. It gets you involved in the emotions of it and everything...* Katherine (54) **FG**

My own observation of the course showed that feelings were a strong focus, and examples of this included participants exploring their feelings in relation ‘fancying’ people and giving/receiving compliments.

In addition and in relation to the way in which feelings were an important inclusion for discussion, the *Sex, Love and Relationships* course seemed to provide participants with a safe space in which to talk about sexuality, underlining the fact that sexuality was something that could be talked about<sup>115</sup> and was an experience relevant to this group. The course also gave respondents opportunities to explore their feelings in relation to sexuality and, sometimes, uncomfortable experiences. Susan, for example, said that the course provided her with an environment in which she could talk safely about herself and her own experiences, and said the following about this aspect of the course:

*Because it's an important thing for me, talking about what's going on, my life...Talking about my own body and that... Susan (56) I*

Susan's comment about being able to talk about her body, and her experiences, echoes Millard's (1994) findings, where women's group members discussing sexuality particularly valued the opportunity to talk about sexual abuse, and have their own experiences listened to.

One of the course leaders commented, once I had completed my observation of the course, that this was the only *Sex, Love and Relationships* course he had been involved in where nobody had been in tears after talking about sexually abusive experiences. This underlines the way in which the course potentially provides ‘safe space’ to talk about sensitive issues. All those interviewees who had reported experiencing negative aspects of sexuality (abuse for example) suggested that they had had little opportunity to talk about their experiences and that they would have liked the opportunity to do so. Although this might have been for a number of reasons, shame or embarrassment for example, Michelle suggested that she could not talk about an abusive

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<sup>115</sup> However, one of the last exercises on the course I observed was for people to ask the ‘rudest’ questions of the planners and facilitators that they could think of. Whilst this ‘opened’ up the space for the discussion of subjects that might have been considered ‘rude’ in other contexts, it also reinforced the association between ‘rudeness’ and sex.

relationship that she had been in because 'I can't tell my mum and dad about it though...I don't want to worry them.' Sobsey (1994) has highlighted the fact, that in the US and Canada at least, support services in relation to sex offences, are difficult for people with learning disabilities to access. However, McCarthy (1999) notes that in the UK, mainstream services are beginning to look at ways of increasing their accessibility for disabled people. (Indeed, within the North East of England, where this study was conducted, Newcastle City Council recently commissioned the Rape Crisis Centre to explore ways in which this might happen, as reported by Howlett and Danby 2007.) In this study, the course was one place in which people had the opportunity to talk about their experiences, important when other opportunities to do so might be lacking.

Whilst I have outlined here perhaps the relatively straightforward ways in which information on sexuality is given on this course, I have suggested earlier that knowledge(s) are not simply about information being given, or not. Knowledge(s) are also value-laden, they convey messages about what is 'good' or 'bad', what is acceptable or not. I would suggest that the very fact that this course discusses sexuality at length in a number of different ways challenges the notion that sexuality is 'not for' people, or indeed women, who have learning disabilities, and that it is not something that is talked about, and is therefore 'dirty' or 'wrong'. Implicitly, by its inclusion of a range of subjects, it suggests that sexuality is something that participants might experience, and deal with. Explicitly, exercises like a role play that explored how a couple might challenge parental and day service denial of their relationship, underlines the notion that people with learning disabilities are both sexual and adult. I include an extract from my observation notes on this here:

Two day service users 'Alice' and 'David' (played by two of the course volunteers) are sat on a park bench. They discuss the lies they've told their parents so they could be together. They say their mums and dads don't trust them (despite being thirty and thirty-four). They want to be treated like adults.

They ('Alice' and 'David') 'should' be at the day service. The day service manager comes to look for them. He is on the phone to 'Alice's' mum, promising that he would try and find them and that he would tell her when he had. He finds 'Alice' and 'David' and tells them that they have to come back to the day centre. They refuse and he says that he will phone their mums and that they (the mums) would come and 'drag them back.'

The role play continued, punctuated by discussion, to include a subsequent meeting about the ‘situation’ between service staff, ‘Alice’ and ‘David’, and ‘Alice’ and ‘David’s’ parents. This meeting gave ‘Alice’ and ‘David’ the chance to talk about not being treated like adults, and to negotiate a compromise whereby they spent time together outside of the day centre, but told staff before they went out. This role play, and discussion surrounding it, gave participants the opportunity to explore their rights in this situation, and ways of negotiating it.

Whilst the course highlighted a number of issues in relation to the sexual rights of people with learning disabilities, and challenged some of the ways in which these might be constrained, I would also suggest that the knowledge(s) conveyed by the course might also uphold and underscore particular kinds of (gendered) sexuality. As I have indicated, men and women were broken into two separate discussion groups at particular points in the course. For example, this occurred when the group were exploring what ‘sex’ was, and how ‘fancying’ someone might feel. This separation might suggest that men and women have different experiences of sex, or different feelings, and that men and women might not feel comfortable talking about their experiences together.

Two role plays in particular reinforced gender stereotypes. The role play described above relating to abuse involved a male abuser and a female ‘victim’. The other role play explored how to approach a potential partner, with the person being approached being a female and the person doing the approaching being a man. Whilst these are implicit references to gender stereotypes, Katherine and Jane (interviewees) referred to a number of ways in which the women-only version of the course might have made *explicit* references. Both referred to learning about how they could attract men, and Katherine described this in terms of ‘how to attract a man’, and how to find an ‘ideal’ man. Both women referred to being given the opportunity to have ‘make-overs’ and Jane talked about the course including information on ‘how to be a woman.’ Quotes relating to these activities include the following examples:

*I learnt that you can emphasise parts of your body, make them more attractive to a man. Katherine (54) I*

Elizabeth: What kinds of things do you do [on the course]?  
 Jane: Like, how to be a woman.  
 Elizabeth: Could you tell me more about 'how to be a woman', what kinds of things do you do?  
 Jane: You wear perfume and you wear make-up as well...and being independent.  
 Jane (39) I

As these activities were not elements of the course I observed, and other courses had included make-overs, it might be that the women were referring to these by accident. However, both women had attended women-only versions of the *Sex, Love and Relationships* course (I attended the mixed-sex course) which *may* have included these activities. When I attempted to verify this with *Sex, Love and Relationships* trainers, none had led this women-only version of the course. However, it was felt that *if* these things had been discussed on a course, it was more likely to have been on a different course to the *Sex, Love and Relationships* course. Nevertheless, the inclusion of these activities at the centre, whether on the *Sex, Love and Relationships* or on other courses, suggests that gender stereotypes were underlined.

Hockey and James (2003) describe the preoccupation of young girls with clothes and make-up as 'the male in the head', suggesting that both women *and* men are influenced by these (hetero)sexualised norms. These discourses potentially limit women's behaviour (Bartky 1988). I would also suggest that they might make a woman feel 'unwomanly' should she choose not to subscribe to them. As Butler (1999) suggests, to lie at the margins of normality is to risk gender unintelligibility.

However, they are also, arguably, invisible as women too, with the label of 'learning disability' overshadowing their status as women (Davies and Jenkins 1997, Baron *et al.* 1999). Historically, women with learning disabilities have been seen as in need of protection and/or discouraged from being sexual, or having sexual relationships (particularly where there is a risk of having children). Any recognition that this group *are* women (however normative) could be seen as some form of (paradoxical) 'progression' (Barron 1997). Whilst feminists would suggest that adherence to normative feminine roles is problematic, Begum (1992:75) highlights the difficulties and tensions that disabled women face:



As disabled women our experiences of institutions such as the family are significantly influenced by the pressure of conventional gender-role distinctions. We either make a positive decision for political or personal reasons not to ascribe [sic] to traditional roles, or we fight very hard to conform to the ascriptions which classify us as “real women”.

The course, in implying that all women’s experiences might be the same as each other’s, or all men’s the same as each other’s, also suggests that these experiences are likely to be heterosexual ones. Although the course more generally included same-sex relationships within discussion (for example, they included same-sex couples in an exercise where participants matched famous couples with each other, and included questions on the ages of consent for lesbians and gay men in a ‘question and answer’ session on ‘the law’), it also implied that heterosexuality was the norm, both by its separation of male and female discussion groups, and its role plays that focused on heterosexual relationships and interactions.

More generally, despite the potential challenge of the *Sex, Love and Relationships* course to the notion that sexuality is ‘not for’ women (and men) with learning disabilities, its challenge sits *alongside* other, wider accounts of sexuality. For example, Jean suggested she did not want a relationship, as seen in the following quote, where the only reason she could give for her opinion was because of her having had epilepsy: ‘I’ve never ever been interested in lads. I don’t know why. Might be the way I was when I started epileptic fits, you don’t know.’ However, despite having been on the *Sex, Love and Relationships* course, and having been involved in its planning and implementation, that:

*Well, I’ve never had a lad in my life, never. If one came to the door I would just chase him away. It never bothers us, never...being on the ‘Sex, Love and Relationships’ course, it still doesn’t bother me. If a lad<sup>116</sup> came (near me) I would just chase him. I don’t want a boyfriend, I never have.*

Jean (66) **FG**

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<sup>116</sup> Jean consistently used the word ‘lad(s)’ when she referred to men (a use I confirmed with her after the focus group where she first used the term). Other women too referred to men as ‘lads’.

This suggests that the *Sex, Love and Relationships* course in itself is not influential enough to dislodge more ‘negative’ understandings of sexuality.

## Conclusion

In this chapter I have highlighted some of the accounts that respondents reported having come into contact with. Although there seemed to be a perceived ‘lack’ of information on sexuality in family and residential service settings, I have shown that although this might seem to be the case, particular accounts of sexuality were nevertheless present. These included what might be described as ‘productive silences’ that suggested that sex was either something that could not be talked about, or is something that was ‘denied’ to respondents on the basis of their ‘difference’ from other people. These ‘silences’, however, sat alongside direct prohibitions that underlined the sense that many respondents were ‘unintelligible’ as sexual subjects. On the other hand these were in some ways challenged and contradicted by the normative gendered accounts that appeared to suggest that a ‘normative’ gendered and (hetero)sexuality was possible. Additionally, wider accounts suggesting that sex was ‘dirty’ and ‘unsafe’, might reinforce prohibitions whilst also reflecting gendered discourses. Some women also learnt about sexuality by being in relationships, and that these could be violent and exploitative. As with some non-disabled women, sexuality was thus cast less in terms of desire or pleasure, than in terms of danger.

The *Sex, Love and Relationships* course was seen as important by respondents in relation to learning about sexuality. Whilst it focused on ‘functional’ biological aspects of sex, it also, in addressing wider aspects, implicitly suggested that sexuality was a part of respondents’ and course participants’ lives. The course was cited by respondents as particularly useful in the way in which it made learning fun, addressed emotions, and operated as a relatively safe space in which to explore sexuality. However, it also appeared that it might have underlined particular gendered discourses in relation to sexuality, along with other courses at the centre.

It is clear that these sexual accounts differ in different contexts and differ between respondents, and that sexual knowledge(s) are, despite the attempt here to tease

out the 'what' from 'where', intersecting and interacting to give each respondent a unique view of what sexuality is, and how it might relate to them. However, it is also true that these accounts represent particular kinds of sexual 'scripts' associated with gender and learning disability, including the suggestion that motherhood in particular, is 'not for them'. The accounts and discourses articulated by the course, whilst potentially challenging other accounts and discourses, also therefore exist alongside and are entangled with them.

In the next chapter I will explore family and institutional practices that were, or have the potential to be, influential on respondents' sexuality.

## CHAPTER FIVE

### Institutional Practices and Their Influence on Sexuality

#### Introduction

In the previous chapter I focused primarily on the accounts of sexuality that respondents reported encountering in family and service settings. In this chapter I will explore the institutional contexts respondents lived in, with particular reference to the more tangible or direct family, service and professional staff practices in these contexts. I will focus here on the ways in which such practices affected respondents' constraint and/or agency, and how they might influence respondents' sexual lives. In relation to service settings I will specifically examine respondents' accounts of *residential* service settings<sup>117</sup>.

Although I make a distinction here between accounts and practices, in reality these intertwine and are difficult to disentangle. In particular, this is because practices can reflect and reinforce accounts and discourses. For example, if a discourse or account suggests that people with learning disabilities should not have sex, and an institution's practices include not allowing people with learning disabilities to have visitors in their rooms, the practice underlines and is congruent with the account/discourse.

In the first half of this chapter I will set out some of the ways in which family practices appear to act, or act potentially, to constrain or facilitate agency in respondents' sexual lives. I will begin this section by looking at the impacts and potential impacts on sexual choice and agency in terms of the way in which decision-making was sometimes taken out of respondents' hands, how transitions from parental to own home or residential care were delayed or failed to occur, and how some respondents experienced abuse within parental or marital settings. In the second half of the chapter I will look at agency and constraint within formal services: in relation to where

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<sup>117</sup> This is because residential settings were both most frequently discussed in terms of service settings, and because their role was arguably more significant. All respondents included in this section lived in twenty-four hour staffed homes (ten respondents in total lived in such homes). In using the term 'residential' I am in this instance including *all* staffed homes, not just those formally designated as 'residential homes'.

respondents lived, who they lived with, and their experiences of day-to-day decision making; and in relation to the effects of social constraint: the way in which day-to-day activities and relationships revolved around specific, limited, heavily supervised and learning disability-specific social spaces.

Throughout this analysis I will highlight a number of issues (some of which I have already highlighted in the previous chapter and am continuing to highlight here) that appear to impact on respondents' choice and agency, including those of capability, dependency and protection; restrictions on transitions from child to adult status; and limitations on social networks and activities. I suggest that these potentially affect what respondents know about sex, the sexual partners they may or may not meet, and the way in which they might be able to live their sexual lives and develop a sense of sexual self.

## Family

### *The Role of Families in Decision-making*

As has already been suggested, the category of 'learning disability' is associated with notions of capability and dependency. Further, as highlighted by the *Valuing People* White Paper (Department of Health), people with learning disabilities 'often have little choice or control over many aspects of their lives' (2001a:2). Rolph *et al.* (2005) have highlighted the way in which families (as in parents and siblings) tend to be central to the lives of people with learning disabilities, and most interviewees in this study reported a relatively high degree of family involvement in their decision-making, as I will show.

Relationships between respondents and other family members were both complex and influential. Although such influential relationships were often associated with parents, it was also striking that four interviewees reported siblings' involvement in their lives. This involvement appeared to assume a pseudo-parental role when parents died<sup>118</sup>. The following example shows how difficult it was for Mary's siblings to see her

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<sup>118</sup> These observations are related to the older women who had lost both parents. More generally, as all the younger women had at least one parent alive at the time of interview, it would be difficult to say whether changing notions related to learning disability might have brought changes for the younger women in the group.

as someone capable of making her own decisions when her father died, resulting in them disagreeing over how to deal with decisions in relation to her life. In the first quote, Mary is referring to when her mother died, and her sister arranged for her to move in with her, and then into a residential home. The second quote was in response to a question about whether or not she would have liked to have lived on her own, after her father had died:

*It was because my sister wouldn't let me live with my dad you see...I didn't really want to leave my dad but my sister said 'Mary, you've been at [Mary's parent's house] for so long, you need some private life for yourself.' She told me to. She said 'If Mary wants to go it's up to herself' and that's what I did. Mary (78) I*

*I would have liked to have had a flat on my own but then my sisters wouldn't let me. Mary (78) I*

In both quotes Mary suggested that one or more sisters would not let her live where she wished, and although one of her sisters appeared to be arguing for Mary's benefit (a 'private' life), it is clear that this was *not* what Mary herself wanted; it seemed to Mary that she was not being listened to. When asked what might be the reasons why her sisters did not want to her to live with her father (from what she reported he would have benefited from her continued presence), Mary told me that she did not know of any. Other interviewees, who had had similar decisions made on their behalf, also reported not being clear on the reasons why those decisions were made, turning this into a shadowy process not deemed to be of their concern.

Sibling opinions in relation to Mary's intimate/sexual life also came to the fore, reflecting the way in which her siblings disagreed over the few decisions she had made in relation to this. Although in the following example, Mary's comments seem to suggest that one sister defends Mary's right to make decisions, which can be viewed positively in light of the previous quotes, in doing so she also denies Mary the opportunity to defend her *own* actions. These examples, as recalled by Mary, refer to

two of Mary's sisters' comments at the end of her marriage, after ten years of physical violence:

*(My sister said) 'You should only have been friends, you should only have seen him at the centre and then been on your own and you would have been better off.'* Mary (78) **I**

*(My sister said) 'It was Mary's own future, she was looking to her own future...she can do what she likes now, and leave her alone.'* Mary (78) **I**

In these examples, Mary had previously been in a position to make the decision to marry, but the first sister criticises this decision by suggesting that she should have 'only been friends' with the man who became her husband. Although this comment might only be associated with the subsequent violence Mary experienced within her marriage, it could also be inferred that as a disabled woman, she should not have taken the risk of having an intimate relationship in the first place, thus connecting with historical notions that people with learning disabilities should abstain from a sexual life (which was linked with marriage<sup>119</sup>, see Craft and Craft 1979, Lonsdale 1990, May and Simpson 2003). It might also be associated with the notion that people with learning disabilities are asexual; Mary's sister might be questioning Mary's 'need' to take a friendship any further by getting married. Mary had, for example, described this relationship in terms of companionship. As already suggested, the second sister potentially denied Mary a voice of her own.

Sibling involvement in decision-making also affected Susan, particularly in relation to her only intimate long-term relationship. Susan spoke of her brother frequently in interviews, and it was clear that she listened to him, and acted on his advice. The following examples relate to Susan's engagement to a man who was one of four residents of the same small residential home in which she lived:

*My brother said 'don't get married, stay engaged, it's expensive to get married'...*  
Susan (56) **I**<sup>2</sup>

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<sup>119</sup> Although companionate marriages based on friendship have also been advocated in relation to this group (Craft and Craft 1979, May and Simpson 2003), as suggested previously.

*He [Susan's brother] didn't want anything to happen to me. If there's anything happens to me my brother will go mad. If (my fiancé) wants to have sex with me, if my brother gets to find out he's having sex with me to have children, my brother would go mad... 'cause he doesn't want us to have sex...*<sup>120</sup> Susan (56) **I**<sup>2</sup>

Susan was one of the interviewees who reported having been the subject of sexual abuse. She had been attacked and raped at a younger age, and when asked if her brother might have been concerned about her sexual safety, she agreed, replying that he 'just wants me to be safe.' Although Susan's brother was clearly concerned for her welfare, and was possibly using the expense of a wedding as an excuse to dissuade her from marriage, it could also be argued that with help and support Susan might have been able to deal more effectively with what had happened to her and to cope with a sexual relationship and marriage (an argument made earlier in relation to Susan in relation to professional staff support). It might also have helped her find the confidence to talk to her fiancé about what had happened to her, something she had felt unable to do. Susan was clear that she would have liked to have talked about what had happened to her, but that she had not had the opportunity to do so<sup>121</sup>.

In these examples, Susan's brother, as Mary's sisters may have been, appeared to be (according to what Susan had said) equating marriage with sex. Susan's brother also appeared to be equating sex with Susan's partner's desire for children, although this might be because Susan's partner did want children – something she might have communicated with her brother. Getting engaged or being in a relationship was not deemed an issue, and it was assumed that Susan was not already having sex. As May and Simpson (2003) have highlighted in relation to men and women who have learning disabilities, historically sex was not necessarily seen as an element of marriage, and people with learning disabilities have to some extent been allowed to 'play' with roles like engagement or marriage, as long as they have refrained from sex or more particularly, having children, which they argue has been the crux of concern in relation

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<sup>120</sup> Although Susan is using the present tense, she is referring to the past.

<sup>121</sup> Why this was the case was not followed up. Abuse was not a topic that I had intended to explore, and it was only in later interviews, after interviewees themselves had brought this subject up, that I deliberately asked respondents about their experiences of talking about abuse, and only after *they* had introduced the topic.



to men, but more particularly women, with learning disabilities. In this instance, and perhaps unusually at this point in time, when sex and marriage are less closely associated than previously (Lees 1993, 1997, Wellings *et al.* 1994, Jackson 1997, Walby 1997), Susan's brother reflects a normative discourse that links marriage with sex.

I would argue that despite the idea that Susan's brother is being protective because of her sexual experiences, there is evidence of a wider desire to protect Susan from other experiences that he seems to feel that she cannot cope with. This desire is effected through the active denial of Susan's wishes, for example, Susan's brother, and other family members, were also involved in shielding her from the deaths of her father and mother, as evidenced in the following quotes:

*And after he [Susan's father] died, I didn't go to the funeral... 'cause I had to go on my holidays, to go away. 'Cause they didn't want me to be there, 'cause it might upset me. Susan (56) I<sup>2</sup>*

*(My brother said) 'I wouldn't trust her to go to the chapel of rest to see her (mother)', because it would upset me. So I just stopped in the house. Susan (56) I<sup>2</sup>*

When I asked Susan 'Would you have liked to have gone to the chapel of rest?' she answered 'I would go, to see her, respect for my mum.' The brotherly, and probably loving, desire to protect Susan invalidated her wishes. It is clear that Susan was unable to 'fight' against this as her acquiescence shows. This veto might also have denied Susan the opportunity to get 'upset', or to 'face' death, suggesting that 'upset' is not something people with learning disabilities (or the people around them?) can cope with. The word 'trust' also suggests that Susan might not just get upset, but might do something that others would find difficult to deal with. This prohibition is akin to the denial of respondents' opportunity to take risks. This questioning of Susan's ability to cope with death (and sexual relationships) also confers on her a childlike status. As already discussed in Chapter Four, respondents spoke explicitly of being treated like children.

However, it is important to acknowledge that people with learning disabilities may resist attempts to control their lives. Jean for example, who used public transport independently, reported that:

*Me sister doesn't even like that. But I don't care, it's my money!...the other ones [siblings] were pleased about it but this one is the only one who's not.* Jean (66) I<sup>2</sup>

*I think she thinks I'm going to fall off the bus. I did once but I'm all right now with it...I haven't said anything yet to her about it...just kept it quiet from her, for now.*  
Jean (66) I<sup>2</sup>

Here Jean resisted both her sister's suggestion that she should not use public transport, and suggested that she did not care about her sister's opinion. Her suggestion that her sister 'doesn't even like that' suggests that the sister makes comments about Jean's life relatively regularly. Jean highlighted the way in which other family members were 'pleased' for her independence and the way in which, although she fell off the bus once (this, Jean said, had caused her sister's fear) she continued to use the bus, much like anybody else. However, it is also clear that Jean felt that she could not openly suggest to her sister that she had ignored her feelings on the matter, and had kept it 'quiet... for now',<sup>122</sup>.

### *Delayed Transitions*

Another factor related to family contexts was the length of time spent living in the family home in comparison to non-disabled groups. *Valuing People* states that 'Most people with learning disabilities live with their families' (Department of Health 2001a:70), giving a national figure of 60% of all people with learning disabilities living with their families, with Rolph *et al.* (2005) suggesting a similar figure. This is a large proportion, although Irwin (1995) has suggested that younger (non-disabled) people are staying at home for longer.

As suggested earlier, four of the older interviewees in this study, aged between mid-forties to late-seventies at the time of interview, reported living with parents until one or both of their parents had died. Orlowska (1995) highlights the way in which many people with learning disabilities only move out of the family home when there is a

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<sup>122</sup> It is also interesting to note that she did not question the right of her sister to know.

crisis in the household, a point also highlighted within the *Valuing People* White Paper (Department of Health 2001a), which underlines the way in which such crises might involve the illness or death of a carer, as in the cases here. In this study, the moves amongst this older group typically occurred when the respondents were in their forties. Additionally, two of the younger interviewees lived with parents: Jane (aged thirty-nine, who though expressing a wish to live with her partner had made no practical plans to do so<sup>123</sup>) and Sally (aged twenty-five, with no plans to leave the family home). Two other younger interviewees did live outside the home, Vicky (twenty-five, who lived in a staffed home and reported that she had left home due to ‘problems’<sup>124</sup>) and Julia (twenty-five, who reported that she had left the family home because her social worker had decided that she should). Given the reasons they gave for leaving home, these two younger respondents might also have remained at home for longer under different circumstances; their reasons for leaving did not appear to be wholly based on choice. Another younger respondent, Michelle, who is twenty-nine, *did* live in a flat on her own but lived above and next door to relatives and expressed frustration at their inability to let her have her independence, describing them as:

*Too much in your face... everyone knows your business.* Michelle (29) I

Hockey and James (2003:57) argue that ‘the...rigid pattern of the modern western life course which emerged in the mid-nineteenth century continues to occupy a hegemonic position.’ Thus, key life transitions like marriage and employment are an integral part of the way in which individuals gain adult status. The *Valuing People* White Paper (Department of Health 2001a) highlights that poor planning has affected young disabled people at the point of transition into adulthood. Based on fifty interviews with service managers and professionals, as well as, and including, interviews with fourteen service users and parents of service users, and follow-up interviews with eighteen key professionals and nine service users/parents in the UK in relation to

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<sup>123</sup> I also sensed that this outcome was unlikely – for example Jane only ever spent time with her boyfriend on her day service work placement, he never visited her home or she his, and the women’s group facilitator intimated that her parents were overprotective (she was surprised for example that Jane’s parents had supported Jane’s involvement in the research, as their previous actions in relation to Jane’s involvement in similar activities suggested that they might stop her).

<sup>124</sup> She chose not to explain what she meant by this on further questioning.

transition<sup>125</sup>, Hudson (2006:49) argues that ‘compared with non-disabled young people, the experience of those with learning disability [of transition] is characterised by wider scope, longer duration and attenuated experiences.’

With reference to the older group described in this study, it could be argued that a ‘normal’ life, and ‘normal’ life transitions, might have involved leaving home to get married. Hockey and James (2003) have argued that marriage has been a particularly important marker of the transition from childhood to adulthood, and citizenship. (For the younger respondents in this study, further or higher education and more particularly employment<sup>126</sup>, and their association with economic independence, might be considered to be the current markers which confer this status, with the decline of the importance given to marriage [Lees 1993, 1997, Wellings *et al.* 1994, Jackson 1997, Walby 1997, Giddens 2001, Jackson 2007]<sup>127</sup>.) In the older group most of the respondents I spoke to had not been or were not married (of the interviewees, one respondent was married and three had been – but of these, one married in her late forties, and one in her fifties, leaving only two who married in their twenties). This possibly explains why some respondents remained at home, when other siblings left.

In addition, two of the interviewees who lived in the parental home until their parents’ deaths, and Katherine, who moved out of the home to marry, returning after her divorce four years later, reported taking on the gendered role of their parents’ carer in the absence of their siblings<sup>128</sup>. Mary describes this role in the following quotes:

*I looked after them since I left school, you see. My two sisters were married, and my brother was nearly getting married, you see, and so on. So I was the only one left at home. Mary (78) I*

*I had a long life looking after my mum. Mary (78) I<sup>2</sup>*

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<sup>125</sup> Respondents included men and women.

<sup>126</sup> Walby (1997) has argued that employment and education have been increasingly accessible to women. Further, Hockey and James (2003) cite employment as a signifier of adulthood. Few (one quarter of the sixteen interviewees) of the women were employed, and none worked full-time.

<sup>127</sup> Hockey and James (2003) suggest that sex is also an important marker that has superseded marriage for younger generations. However, May and Simpson suggest the opposite, that with (they argue) the decline in significance of employment as a signifier, marriage, and more particularly parenthood, may now ‘constitute perhaps the defining stages in a journey from childhood to adulthood’ (May and Simpson 2003:28).

<sup>128</sup> Although it also likely that men with learning disabilities also take on this role.

The role of a person with a learning disability caring for others is a relatively unacknowledged one, whereby those seen to be in need of 'care' themselves act as carers (which might explain why it is unacknowledged); it is difficult to reconcile the idea of someone who has a learning disability, someone who is defined by their lack of capacity, with the idea that they are capable of taking on such a role. This role is additionally, when applied to the general population, perceived to be a gender-related one, and is more usually taken on by women (Finch 1989, VanEvery 1996, Skeggs 1997). Here the agency conferred by the move from the family and childhood home on marriage (or in the younger respondents' case employment or vocational or higher education) is limited, with this limitation compounded by its relationship with gender. There is also a suggestion, in Mary's case, that this role was taken on as a default; she was the only person left at home so it was 'natural' that she should adopt it. Although it can be argued that non-disabled women frequently take on the caring role with adult family members, I would argue that the additional lack of opportunities that the older interviewees in the study felt they had to marry and leave home, and the younger interviewees to find employment, increased the likelihood of this happening for the respondents here.

Mary's experiences of looking after her parents limited what she could do, where she could go and who she could meet. This seemed to be compounded by the lack of support she received from her siblings, suggested by her concerns that she could not leave her parents, inferring that her siblings saw no reason to relieve her of her role and give her the opportunity to go out. This points to a lack of awareness of Mary's siblings of her need for social and physical space. Mary expresses her limitations in the following quotes, which also express her feelings of responsibility towards her parents:

*I didn't go out very much when I was looking after my mam and dad...but you see I was frightened to leave them...there was nobody to look after them if I went out you see. Mary (78) I*

*Oh, I felt terrible when I couldn't go out. Mary (78) I*

Many interviewees, like Mary, described having limited social circles, particularly when living in the family home, with friends and acquaintances restricted to family and family friends. Although marrying in her twenties, Katherine – who referred to having had little opportunity to mix with either boys as a child (she went to a single-sex school, unlike her sisters) or with men when she was older, met her husband through family connections. This is described in the following quote:

*Well, it was strange really because his grandmother-in-law is my grandmother. And I was at his grandparents' house one day and she says 'by the way, this is my grandson.' And that's how we met. I met him at his grandparents, you know. And a few weeks later he was there again. And then he invited me up to meet his parents, and that was it, you know. Katherine (54) I<sup>2</sup>*

As suggested in relation to Mary, not having the option to get married might have delayed the transition from family home to independent life for some of the older respondents. For Katherine, marriage *was* an option, but despite the way in which this marriage was seen by Katherine as a form of liberation from her family and childhood home, she commented:

*I felt like I had exchanged one restrictive place for another, if you get my meaning? I felt as though I hadn't been allowed to have any freedom whatsoever...I felt as though I had exchanged one set of rules for another, you know. Katherine (54) I<sup>2</sup>*

Here Katherine clearly felt the restrictions of living at home, believing, in her opinion, wrongly, that marriage would lead to an end to them. Non-disabled women might also have expressed similar wishes and disappointment; however, Katherine reported having made the decision to leave her family for married life with little or no experience of what men were like. As suggested earlier, she reported that she felt that she had been 'protected' from men, unlike her sisters, and that this was directly linked to her having been categorised as having a learning disability. Katherine also reported that her prospective husband was the only man who showed an interest in her, and because of this she decided to marry him. Like many of the interviewees, Katherine reported having had limited social networks – particularly in relation to men who she felt she did not

‘know’ or ‘understand’. Further, it seems that other routes to independence were not available. This last example suggests that even where ‘ordinary’ or ‘normal’ transitions were made, some respondents experienced constraints related to being labelled as having a learning disability that made it difficult for them to lead ‘ordinary’ or ‘normal’ lives.

### *Experiences of Abuse*

McCarthy (1999) cites a number of research studies which suggest that people with learning disabilities (both men and women) are more likely to experience sexual abuse than the general population. Sobsey’s (1994) work identifies a number of reasons why this might be the case, including inadequate knowledge, lack of assertiveness, and the location they find themselves in as a result of having been labelled ‘disabled’. In the previous chapter I suggested that respondents’ experiences of relationships and sexuality were informed by, and contributed to, their understanding of sexuality. I suggest that negative experiences in relation to relationships and sexuality might act as constraints on respondents’ own sexuality (Kelly 1988). In relation to family, two interviewees, Susan and Charlotte, reported being sexually abused by family members.

These experiences clearly affected these respondents’ knowledge of sexuality, as well as how they acted later in their lives in relation to their willingness to have relationships. This can be seen in the following exchanges with Susan, who had been sexually assaulted, first by a brother and then by someone else (though not a family member) that she knew:

*Elizabeth: Do you think that this experience has affected the way you view men?*

*Susan: I would meet men, but don’t go out with each other. I’d just talk to them. I wouldn’t go out with them. I wouldn’t go out any more with them.*

Susan (56) I

*Susan: I don’t want men to have their thing between my legs, because I saw a programme about people going to bed together. And you could see them lying on top of each other...It was absolutely*

*painful. I said 'I'm not going through that', because they could have their sperm into you. Because that's what happened to me.*

*Elizabeth: Do you ever think you might be 'missing out' on sex?*

*Susan: No, I wouldn't like it, it would scare me. I could feel it now, I can get the feelings now. Because when someone mentions it, it just upsets us.*

*Elizabeth: Just talking about it?*

*Susan: Oh aye. My inside goes up, aye.*

Susan (56) I

In these examples Susan's experience of sexuality has been constrained in a number of ways. Firstly, although Susan suggested that she did not want a relationship, she described having had one relationship with a man, with whom she was engaged. Susan reported that although her partner wanted to have sex with her, and to have children, she refused him. She told him that she disliked him touching her breasts, and also reported feeling uncomfortable with him kissing her on the lips. Susan did not feel able to tell her partner what had happened to her previously and this made their relationship difficult as he was unable to understand her reasons for not wanting to participate in sexual acts. Susan's experience also appeared to affect her 'reading' of television programmes depicting sex, as evidenced in the second quote. Susan perceived sex to be painful regardless of whether these images were intended to be positive or negative, and was unable to accept, when I asked her, that sex might be enjoyable. This might be explained in terms of Gagnon and Simon's (1974) sexual 'scripts', in that Susan learnt via her own experience that sex was painful and traumatic, and therefore linked this 'script' to other people's experiences of it.

Sex was something that Susan found difficult to talk, and even think, about. Sexual abuse was a form of practice that ultimately constrained Susan, and two other interviewees', subsequent sexual lives. Arguably, this is also the case for many non-disabled women (Kelly 1988). However, as suggested, a number of factors increase the possibility of women with learning disabilities experiencing sexual abuse. Importantly, all the women I spoke to who had experienced sexual abuse suggested that they found this experience difficult to talk about. They did not seem aware of the support services that might be available to them that might have made it easier for them to 'work through' their experiences, and 'move on' to have a 'normal' life.



In this first section of the chapter I have explored some of the family practices that might have influenced respondents' ability to exercise agency. I will now go on to look at the ways in which residential services and residential service practices might have influenced respondents.

### **Formal Institutions**

As well as 'producing' particular accounts of sexuality, formal service providers, like families, are also potentially influential in relation to their *practices* on the agency and choices of service users with learning disabilities. As I have suggested, general policy relating to people with learning disabilities and more particularly the *Valuing People* White Paper (2001a) highlight the need to ensure that people with learning disabilities have choices in relation to all aspects of their lives, as well as rights, independence and inclusion, and requires that services work towards these aims. However, Harris (2003) has argued that people with learning disabilities do not necessarily know what choices (which are limited anyway) are available to them. Studies have suggested that staff working directly with people who have learning disabilities influence the level of choice that this group have, sometimes in seemingly negative ways. McCarthy's (1998a) study shows the often unwanted influence of others, including staff in service settings, on women with learning disabilities in respect to choices about their hair, clothes, weight and contraception. Furthermore, general constraints specific to the circumstances that people with learning disabilities experience, such as lack of privacy or independence, can also impact on choice, as I will highlight here. These constraints also have the potential to affect the ability of people with learning disabilities to develop sexual lives and a sense of sexual self by limiting their opportunities to find and conduct relationships. As argued previously, normalising practices within concepts such as normalisation and SRV, might act as further, but perhaps less obvious, constraints – particularly in relation to gender and (hetero)sexuality. In the following section I will explore aspects of constraint and agency in relation to service settings, with a particular focus on residential service settings.

### *Experiences of Long-stay Institutions*

Life for people with learning disabilities in long-stay institutions<sup>129</sup> has been relatively well documented (for example, Ryan and Thomas 1987), and it is clear that life in these institutions was difficult. Two of the interviewees in this study, both women aged over fifty, referred to living in long-stay hospitals earlier in their lives (the running-down of these institutions accelerated in the 1980s making the younger women less likely to have lived in these sorts of institutions).

Dorothy, who lived in one of the local long-stay institutions for a short time<sup>130</sup> was so upset by one experience that she talked about it at the focus group (unprompted) and at both her first and second interviews. Her comments showed the lack of autonomy and the anger she felt in this setting, and referred to an incident when staff ‘permed’ her hair without her consent, as seen in the following exchange:

- Dorothy:*     *I didn’t like it, it was a long time ago...I couldn’t stick it... First day I went there, guess what? My hair’s naturally curly and you know what? They did my hair, permed my hair.*
- Elizabeth:*   *Who decided that?*
- Dorothy:*     *Them, and my hair can’t perm, because it’s naturally curly, and my hair went really tight, took two hours to get the perm out!*  
                    *[voice raised].*

Dorothy (60) **FG**

These comments, as well as showing Dorothy’s dislike of the institution, reflect the way in which even very basic decisions about how to style her hair were taken away from her. This experience, though taking place at least seventeen years previously, seemed to dominate her recollections of the institution. Such control, directly exercised by staff over the individual’s body (or experienced as such), reflects the control discussed in McCarthy’s (1998a) work as highlighted earlier, and reflects also the routine ‘invasion’

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<sup>129</sup> By long-stay institutions I refer to large-scale hospitals, often located on the outskirts of towns and cities that specifically housed people with learning disabilities.

<sup>130</sup> Dorothy was unable to say exactly when that was. Given the history she gave me this might have occurred anywhere between the ages of approximately twenty-five to forty (Dorothy had lived with her parents, then her sister, then her brother, then two other group homes before settling in her current home in which she had lived for nearly seventeen years. Dorothy lived in the long-stay institution for a brief period which seems to be around the time that she was living with her siblings.

of bodily privacy and control so often experienced by this group and disabled people more generally (Brown 1983, Sinason 1994). It also echoes the experiences of Jeanette, as described in the previous chapter, with her seeming lack of control over issues of contraception, sterilisation and possible abortion. These instances are evidence of the ways in which staff were able to ‘discipline’ women in these institutions (Foucault 1991).

Jeanette, who had lived in the same institution (but for what appeared to be a longer period than Dorothy<sup>131</sup>) also described living in the institution in negative terms. She particularly talked about her lack of independence and choice, and about physical attacks from a particular staff member, as seen in the following examples:

*I wanted my independence. I'd had all my own choices taken off me and everything...I wasn't allowed my own choices and my own rights and my independence. Jeanette (50s) I*

*I got my head banged and pulled and everything by [names a man]. The staff at (the hospital), on ward [gives ward number]...he just went and threw me on the floor, banged my head off the wall and I had a big bump on my head. Had my hair pulled and everything off him. Jeanette (50s) I<sup>2</sup>*

In the first quote Jeanette used rights-based terms; using words like ‘independence’, ‘choice’ and ‘rights’ in relation to what she wanted at that time. This perhaps reflects Jeanette’s heavy and subsequent involvement in rights-based activities at the organisation where the women’s group met, where she had been involved in talking to professionals about her experiences in the institution highlighted here. However, it is also possible that Jeanette was aware of these concepts *during* these experiences, or at least the desire for agency and control over her life regardless of the language that she might or might not have used at that time, an awareness that would have made her experiences particularly difficult.

In the second quote Jeanette reported that she had told the ‘head one’, which I took to mean the person in charge of the institution, about what had happened to her, but

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<sup>131</sup> Jeanette, like Dorothy, was unable to say exactly when she had lived in the institution. Additionally, the information she gave me in relation to where she lived afterwards was somewhat muddled, but from what she said she had lived in at least two other homes in the community. Jeanette could have been living in the institution anywhere from her late teens to her mid-forties from the information she provided.

that the member of staff who had attacked her continued to work at the institution. Although Jeanette had felt able to tell someone about what had happened, nothing was done about it, from her viewpoint, reflecting and underlining the way in which her agency was constrained, and putting her at continued risk. It is also pertinent that it was in this institution that Jeanette was sexually attacked by a fellow resident, possibly on more than one occasion. Despite this it is important to note that on both these occasions – the attack by a resident and the attack by the member of staff, Jeanette was able to report on what had happened to her, and to recognise that these things should not have occurred. This suggests that despite the constraints experienced within this institution, Jeanette was able to exercise some degree of agency.

Jeanette's reaction to living at the hospital was to present what services describe as 'challenging behaviour'. She describes this in the following exchange:

*Jeanette: I used to scream the place down and everything...it wasn't very good at all...*

*Elizabeth: How did you feel about that time in your life?*

*Jeanette: Awful about it...I had to get out. I was sick of it you see and I was fed up with it when they treat me badly and I put out windows when I was younger. I beat people's heads open and all that and knocked them out and all that...I was drugged you see, I was drugged with injections and tablets and all sorts.*

Jeanette (50s) I<sup>2</sup>

As suggested by the Department of Health, challenging behaviour is usually associated with an individual's lack of control; not being 'heard': 'Challenging behaviours are best thought of as being a way in which people respond and try to gain control over difficult situations' (2001a:103). In this case I would argue that Jeanette's actions were, both as she says because she was 'sick of it' – the bad things continued and would not go away, and because she was not being listened to – Jeanette had told the 'head one' that she was being attacked, but the man responsible still worked with her.

Additionally, as suggested, Jeanette felt that she was being denied her independence, choices and rights. The move out of the institution was, she said, something she had asked for. This meant that eventually perhaps she *was* listened to, although the move may also have been due to the shift in policy from providing care in

such institutions to providing care in the community. Jeanette's response to leaving this institution is illustrated by the following quote:

*I was glad to get out. I clapped my hands as well, I was happy.* Jeanette (50s) I<sup>2</sup>

Jeanette, who never used the word 'happy' to describe experiences within the institution, was 'happy' to leave. Although not necessarily finding life easy in other homes, Jeanette never described them in such negative terms, nor resorted to challenging behaviour to express her needs. This suggests that there was a lessening of the constraints that she had experienced, which was supported by her assertion that she now had more independence

#### *Experiences of 'Community Living'*

As highlighted in Chapter Four, fourteen respondents reported having contact with professional staff within their homes. In addition, all the interviewees had had contact with day services specifically for people who have learning disabilities. This represents a large professional presence in the interviewees' lives. Although the majority of interviewees reported no incidences of direct constraint resulting from staff intervention in their lives, four of the interviewees did. As previously suggested, this is significant because current national, local and organisational policies reflect the need to promote choices and rights for people with learning disabilities, with the support of frontline staff. Instances where staff fail to work towards these aims represent a failure in policy at the point at which it is implemented. As suggested in the previous chapter, a small but significant minority of interviewees reported prohibitions on sexual choices whilst living in residential care.

More generally, interviewees reported other prohibitions, suggesting that prohibition and lack of agency was relatively prevalent in their lives. This can be seen in the following examples:

*She [carer in a family placement] took all my money off me, and I never got any pocket money off her.* Anne (55) I

*Oh, the staff don't let me share the kitchen or anything, they cook the meals you see. They don't let, they don't like [breaks off]. We cook our own meals at college, I go to college on a Tuesday and we cook...The kitchen at home, they never say 'Mary, come and help us with the tea' or anything. If they did that it would give me more experience for the Tuesdays<sup>132</sup> you see, but they don't. I would love that! But I don't like to say anything. Mary (78) I<sup>2</sup>*

Although choice is explicitly discussed in national and local level policy, as both the aim of services and the rationale for staff (supporting people with learning disabilities to be 'independent'<sup>133</sup> is seen to be the aim of professional staff, rather than more traditional notions of 'care'<sup>134</sup>), this choice is clearly undermined in these examples by 'older' discourses of control that reflect the way in which some staff perceive their role as a pseudo-parental one (Forrester-Jones *et al.* 2002, Clements *et al.* 1995) that directly constrains respondents' ability to exercise agency. This approach is validated by the concept of 'ordinary living' that underpins the principles of service provision, and which implicitly suggests that 'ordinary' means living as (or like) a family. Williams (2002) for example, a supporter of normalisation and social role valorisation, explicitly connects these concepts with the provision for people with learning disabilities with a kind of 'family life'. Although it has been the norm for carers to 'control' individual's money (on the basis that people with learning disabilities are not always able to 'handle' it)<sup>135</sup>, Anne perceived that her *right* to have pocket money had been taken away. This again hints at the notion that people with learning disabilities are 'eternal children', unable to 'deal' with everyday 'normal' life. One marker of adulthood – and citizenship – is the right to engage in economic life, particularly in contemporary society via consumption; restricted access to money, or control over how it is spent, thus impacts on an

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<sup>132</sup> Mary is referring to the Tuesdays when she cooks at college.

<sup>133</sup> I use inverted commas here since disability activists and writers suggest that this is often a particularly specific kind of independence, an independence that stresses the importance of disabled people (and people with learning disabilities) learning how to do things by themselves *rather* than independence in terms of being able to make decisions (which they feel is often denied to them and/or not focused on) (Bracking 1993, Morris 1993a).

<sup>134</sup> Although the word 'care' is still used in particular contexts, most obviously in its widespread use to describe professional staff as 'carers' or 'care assistants'.

<sup>135</sup> This is changing somewhat as 'supported living' is being introduced across the UK (see Chapter One). In this model it is assumed that the 'client' takes as much control over their own lives as possible. This ideal had been in place previously but has been emphasised with the increase in 'client' control – as one respondent reported, she now kept her money in a locked drawer in her bedroom, which she had not done previously.

individual's access to this marker. Indeed, the way in which Anne refers to 'pocket money' is particularly childlike<sup>136</sup>.

In the second quote, Mary expressed her frustration at not being, in her opinion, allowed to make meals in the communal kitchen in her home. She suggested that doing so would allow her to practise what she learnt in her college course. Since college courses for people with learning disabilities are largely provided on the basis that they help this group develop 'life skills', Mary's development of this particular skill is not taken forward in practice, rendering her cookery classes primarily recreational. It is interesting to note that Mary referred to her home as 'the home', rather than 'my home', throughout the interview, underlining the sense that this setting was not one that 'belonged' to her. Bigby and Fyffe's (2006) Australian study, based on 250 interviews and 400 telephone surveys with the carers and parents of men and women with learning disabilities on their relocation from long-stay hospitals into the community, as well as observation of the service users themselves, and documentary analysis in relation to the transition, showed that 'daily routines were organised around the necessity of getting things done rather than resident engagement in the running of the household' (2006:573), and this provides one explanation for Mary's experience here.

Most of the interviewees living in group homes reported having had no choice over where they lived, an issue highlighted both by Tøsseboro (2005) and Traustadóttir and Johnson (2005). The *Valuing People* White Paper (Department of Health 2001a) reports that at the time of its publication, only 6% of people with learning disabilities had control over who they lived with, and only 1% had control over who cared for them. Four interviewees reported having moved from previous homes because they 'had to' rather than because they chose to. For example, Dorothy, Jeanette and Susan had moved homes when the larger residential homes they had been living in were closed. Although this was probably due to the policy move from providing care in larger residential homes to smaller group homes for the perceived benefit of people with learning disabilities, this move also represented a significant lack of *individual* control over an important aspect of these respondents' lives. Jeanette expressed how she did not want to move, but how this decision was imposed on her, as seen in the following quote:

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<sup>136</sup> Although this is similar to older generations of women talking about 'pin money'.

*I didn't want to move, I didn't want to move. I liked the house...I had to go into a tenant house you see. A tenant house, like a private house. Jeanette (50s) I<sup>2</sup>*

Although I did not ask Jeanette who had made this decision, it was likely to have been her social worker or care manager<sup>137</sup>, as was the case with other women who had also moved from one residence to another, as I will go on to discuss. Although liking the house she was moving to, Susan described how she was taken to see the house but was not able to go inside, because the couple living there had not yet moved out<sup>138</sup>, as evidenced in the following quotes:

*(We) just walked past the house...And she asked me [the support worker Susan was with] if I liked this house and I said 'yes.' She said 'that's the house you're going to move into.' Susan (56) I*

Describing the same scene, Susan said:

*I loved it, I loved it from outside. But we couldn't come inside 'cause there was a couple in here. Susan (56) I<sup>2</sup>*

Like other respondents, Susan did not perceive this lack of choice to be problematic, telling me how she had been able to choose the furnishings and colour of her bedroom. This suggests that she had particularly low expectations of the level of choice she could expect in relation to her home. These low expectations were reflected in other respondents' accounts, an issue that will be returned to later.

Brown and Croft-White's (2000) study of disabled people and sexual rights reflects the findings here. It showed that for many disabled people, residential care had been their only available 'choice' of habitation, suggesting that in fact there was no 'choice'. Given that the notion of choice is central to learning disability-related policy, these examples suggest that this is often an 'ideal' rather than something available in practice. This reinforces the idea that quasi-market (and neoliberal) approaches to

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<sup>137</sup> Since the mid-to-late 1990s, care managers have taken over the responsibility for dealing with the social care of people who have learning disabilities, although some of these are trained social workers.

<sup>138</sup> Although I did not ask Susan about this further, it can be inferred that either the couple did not want those moving in to look around the property whilst they were still there, or that it was more generally assumed that Susan and her housemates had no need or desire to go inside their future home.



providing services might limit rather than provide choice for service users of support services (Burton and Kagan 2006).

It might also explain why services were so unable to meet the needs of Liz and her husband, who married and lived apart for nearly a year before they moved in together<sup>139</sup>. Neither Liz nor her husband had physical impairments which might have made finding suitable housing more difficult. This suggests that Liz and her husband were not catered for, perhaps because of the difficulty in finding economically viable housing and professional support. On the other hand it might reflect a lack of expectation that even when married, they would live (or even desire) an ‘ordinary’ married and sexual life.

Social workers and care managers seemed to be central to decision-making in relation to where respondents lived, as evidenced in the following quotes:

*That wasn't my choice...it was the social worker's choice.* Julia (25) I<sup>2</sup>

*The social worker done that [decided where Anne would live].* Anne (55) I<sup>2</sup>

Julia reported that she might have liked to have lived with her father but had been told she could not do so by her social worker. When I asked her whether she thought that this was *her* (Julia's) choice, she replied ‘Oh, I don't know.’ Julia in particular appeared to have very little awareness of her own rights – both in terms of where she lived and in terms of her sexual choices (as highlighted in the previous chapter). Additionally, the central role of the social worker in Julia's life is underlined; with the social worker as professional holding power, rather than service user (Chadwick 1996, Helldin 2000).

All the interviewees who lived in shared houses also described having little or no choice over with whom they lived. Forrester-Jones *et al.* (2002), who conducted interviews with 196 people with learning disabilities and 102 mental health service users in the UK, also found that their respondents, both male and female, experienced this. Julia's comments reflect this:

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<sup>139</sup> This information was gained, at Liz's request, from her support worker, as Liz was unable to explain or give me this information in a way that I could understand.

*Elizabeth: Do you like living with other people, generally?*  
*Julia: It wasn't my idea, it was the social worker's idea.*  
*Elizabeth: Would you like to live somewhere else?*  
*Julia: I cannot because I've got no choice.*  
 Julia (25) I

Julia not only felt that she had no choice about where she lived or who she lived with, but also that she could not *change* her situation.

None of the interviewees living in shared group homes reported that the people with whom they lived with were people that they considered to be their friends. This is evident in the following exchange with Anne, who often spoke about having bad relationships with others in the previous homes that she had lived in:

*Elizabeth: So you lived in a house with some other people. Were they your friends?*  
*Anne: No*  
*Elizabeth: How did you get on with them?*  
*Anne: Not very good...they were not very nice to me, they weren't very nice at all.*  
 Anne (55) I

Others reported having negative experiences of living with others, including experiencing physical aggression from fellow householders. This is reflected in the following quotes:

*She got her temper up...she shouts and bawls, swearing, throwing things around downstairs. And I moved out of the way. She's thrown things at me in the living room. A pair of scissors. Susan (56) I<sup>2</sup>*

*[An ex-householder] wrecked the house up and everything and she got taken to [the local long-stay hospital for people with learning disabilities]. She spilled a hot cup of tea on my arm. She used to knock the lamp and the coffee table and the ash trays and used her stick, used to hit the staff with her stick. Jeanette (50s) I<sup>2</sup>*

This level of aggression is both difficult to live with and constraining, and makes it potentially and particularly difficult to bring friends or partners home. It also mirrors the frustrations expressed by respondents themselves who, as previously highlighted, had

sometimes used physical violence to express the lack of control they had over their lives. Goble's study suggests that other residential and day service users were problematic for the respondents he interviewed, who were described in terms of 'irritators or tormentors' (1999:454). Forrester-Jones *et al.* (2002) also found this to be the case for those in their study in relation to residential services, with noise levels, personality clashes and bullying cited as particular issues.

It is notable that the woman Susan described had wanted to live in another house, but had not been able to, and that Susan felt that this woman's 'temper' as she called it was to some extent related to this. It is also interesting to note that Jeanette's reactions to violence within residential settings were different to Susan's. Although both women reported that they would leave the room if someone became violent, Jeanette was more comfortable with violence generally, stating that despite the violence she felt 'safe', whereas Susan, who had been attacked by a previous male householder stated that she was 'absolutely scared stiff of him.' Although this might be because the attacker was male, it is also possible that for Jeanette, who had been violent with others herself, this behaviour was 'normal', although Susan too had experienced other violent incidents in her life, including rape.

As discussed in the previous chapter, Jeanette too reported being raped by a fellow resident in the long-stay hospital she had previously lived in. Being sexually abused in the home constrains choice and agency both *during* the period of the abuse and also *after*. Being abused within the home constrains through the lack of control an individual might have over that situation, whilst afterwards constraint is, or can be, related to the way in which sex and/or relationships are avoided. Jeanette for example decided that she would never have sex again after leaving this situation, saying 'I've not wanted sex since.' Similarly she did not want to have a relationship. Whilst non-disabled women experience sexual assault, as Sobsey (1994) suggests, living in or using spaces specifically related to having a learning disability is likely to increase the chances of people with learning disabilities, both men and women, of being abused.

Privacy is also an issue for anyone living in a group home. It can be argued that as relationships in these contexts are not based on either family relationships or friendships based on choice, that privacy might be more important and necessary.

Dorothy, for example, told me that it was important for her to keep her money locked up – not something that most people have to consider. Although none of the respondents reported that they *did not* have privacy – Liz for instance lived with her husband with twenty-four hour support from staff, yet did not feel like they impinged on her or her husband’s privacy – what some of the interviewees told me appeared to be evidence to the contrary. Susan, for example, felt that she did not always have her own ‘space’ and that other service users were sometimes ‘nosy’. Further, Susan’s ex-fiancé still lived in the same house as her, and she reported the following:

*(He)comes up and barges straight in. And I said ‘you shouldn’t come straight in when I just want to be on my own.’...he comes straight in, he doesn’t knock.*  
Susan (56) I

This happened regularly despite staff intervention<sup>140</sup>, and often led to the man, she suggested, ‘shouting’ at Susan. When Susan told me that this man was moving, and I asked her if this was a ‘good thing’ or a ‘bad thing’, she replied ‘I think it’s good.’

Carers also occasionally invaded privacy. When I interviewed Deborah in her bedroom a carer came in while we were talking, failing to knock. When I was interviewing Susan her carer knocked, but walked in immediately after this without waiting for Susan to confirm she could come in. Anne, who lived in a family placement with a paid support worker<sup>141</sup>, reported the following:

*Sometimes she [carer] does [knock] and sometimes she doesn’t.* Anne (55) I

Barr *et al.* (2003) also found that the male and female service users they ran focus groups with in the UK about accommodation, complained that staff walked into their rooms without knocking first. This level of intrusion and familiarity – especially the

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<sup>140</sup> This also suggests that little consideration was given to whether or not it was appropriate for Susan and her ex-fiancé to continue living in the same house and/or suggests that there might not have been alternative options. Unfortunately I did not talk in-depth to Susan regarding her wishes in relation to this although she appeared to find her (ex) fiancé’s presence in her home problematic, most often referring to him as demanding of her time.

<sup>141</sup> I would suggest that the familiarity of this arrangement, with its emphasis on the notion of ‘family’ increases the possibility that professional boundaries are broken, and further that paternalistic or parental (and controlling) approaches to care are made more possible.

examples where the respondents had a visitor (me), suggests that leading a sexual or intimate life might be difficult or constrained<sup>142</sup>. Furthermore, the way in which respondents failed to perceive this as an invasion of privacy suggests that it is something they are used to; it is 'their' norm. It is possibly for this reason that Julia, cited earlier, did not really know *how* she felt when she was told she could not do particular things or have certain choices: this was the norm. It also suggested, as does the lack of concern amongst respondents in relation to privacy, a lack of knowledge in relation to rights.

Dorothy and Jeanette, who had lived in large institutions, expressed being happier in smaller group homes in the community. Jeanette illustrated how important it was for her to have control over everyday matters, expressing this in these examples:

*I like it all the time and I'm happy there...I'm more independent. I'm in a more independent house. Make all the sandwiches you want, have a yoghurt, anything, have a bit of fruit, anything like that.*

*Jeanette (50s) I2*

*...new clothes every time you want...summer clothes, winter clothes.*

*Jeanette (50s) I2*

Forrester-Jones *et al.*'s (2002) respondents also placed great emphasis on independence in relation to everyday decisions. However, these comments express how low Jeanette's expectations were. Like Susan, who was unable to make a choice over where she lived, but was able to decide on the colours of her room, Jeanette's choices were limited to minor ones – what to eat and wear. These choices were, nevertheless, seen in terms of 'independence'; arguably a narrow concept of what independence might mean. Although there were examples of sympathetic and supportive staff in respondents' comments, an overriding lack of agency over major life decisions, and many minor ones too, gave an overpowering sense of constraint to respondents' accounts of their home lives.

These examples, and those given earlier in relation to where respondents lived, who they lived with, and what they could do in their own homes, suggest that although staff are employed to support people with learning disabilities to exercise choice, control

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<sup>142</sup> In addition to these factors, it is interesting to note that of the three respondents interviewed in their bedrooms, all had single beds. In this way, services appear to provide accommodation on the basis that service users were unlikely to have sexual relationships (and therefore, need a larger bed).

and agency, some of the things they do (and say, as highlighted in the previous chapter) suggest that this is not the case. Policy based on placing service-users at the centre of service-provision is clearly undermined by the lack of choice and power these respondents express in relation to residential services. As suggested, this relative lack of control both highlights the difficulties these respondents might face in attempting to have a sexual or intimate life (historically seen as ‘not for them’), but it also takes place within an environment that constrains such choices through a limited range of options and a lack of private ‘space’ in which to lead such a life.

### *A Social Life?*

Having a social life helps people develop and maintain significant relationships, including sexual relationships. However, Davies (2000) has suggested that:

Lack of physical and financial access to where the rest of society work and play has meant we (disabled people) are disadvantaged in opportunities to meet people and acquire sexual and relationship skills through practice and normal socialization processes.

Respondents’ day-to-day activities appeared to be relatively limited in scope (both in relation to those living in services, and those living with parents). These activities tended to focus on spending time at home during the day (Suzanne for example, when I asked her what she did during the day replied ‘Just cook’), or in settings specifically used by people who have learning disabilities, such as day services<sup>143</sup>, specific college courses and the organisation where the women’s group met. Although most interviewees accessed adult education courses in the community, and two also accessed church-related activities, including services and coffee mornings, all interviewees *also* relied on activities and social spaces specifically for people with learning disabilities. Night-time activities were frequently limited to similar organised spaces, such as clubs specifically for this group.

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<sup>143</sup> It is interesting to note that a 1999 Department of Health report states that two thirds of people with learning disabilities attended ‘large, congregate day centres’ (Cocks 2002). Further, Barnes (1990) has described day services as ‘dumping grounds’ for disabled people, and the government has suggested that ‘some large day centres offer little more than warehousing...’ (Department of Health 2001a).

Four interviewees were employed, with none in full-time work. The Department of Health (2001a) suggests that few people with learning disabilities are employed nationally. This has a number of potential impacts. As already suggested, having control over money is a signifier of adulthood and citizenship, as is gaining work. Work is also an important source of social interaction. Forrester-Jones *et al.* (2001), for example, found that the social networks of the men and women with learning disabilities in their study increased on gaining work<sup>144</sup>. However a wider study (Forrester-Jones *et al.* 2002) showed that the majority of the people they spoke to beyond this smaller group were neither in education *or* employment. It is clear that, more generally, people with learning disabilities are denied the range of social opportunities that most non-disabled people have access to. This means that they are less likely to mix with non-disabled people, despite policy aims of ‘inclusion’, and that they have restricted social contexts for meeting sexual or intimate partners.

Five interviewees relied heavily on the centre where the women’s group met, attending the centre more than once a week. These women helped run courses, and attended the women’s group and drop-in. In addition, all the interviewees had used the centre outside of their time spent at the women’s group. The informal space of the drop-in seemed important in terms of having somewhere that people with learning disabilities could spend relatively unsupervised time (staff worked in the building but not in the drop-in room), and meet up with friends. Nevertheless, it remained a segregated space ‘just’ for people who have learning disabilities (both men and women), and had the air of somewhere where people might go simply because there was nowhere else to go – an inference ‘backed up’ by the women’s group facilitator who felt that some users were over-reliant on this space. Furthermore, users tended to access this space on specific days, when free taxis were made available to them. As I will go on to suggest, travelling caused some respondents problems.

Some of the reasons given for attending the centre more generally (both the drop-in and the courses) suggest that boredom (as suggested in Goble’s study of 1999 and

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<sup>144</sup> This involved a study of eighteen men and women with learning disabilities who were using a supported employment agency.

Forrester-Jones *et al.*'s of 2002) was a significant incentive, as well as loneliness (as suggested by Forrester Jones *et al.* 2002), as seen in the following examples<sup>145</sup>:

*(I go) just to get out of the house really. Michelle (29) I*

*To meet people...just more people. Vicky (28) I*

*Well it's company. Anne (55) I*

In addition, my Masters research on adult education for people with learning disabilities (Brace 2002, unpublished) showed that the people with learning disabilities<sup>146</sup> who took part in the research also attended courses because of a lack of things to do. This led to some of the interviewees repeating courses a number of times. Similarly, one respondent in this study had attended courses, including the *Sex, Love and Relationships* course, more than once. Jane reported:

*I just do them, a whole lot of times. Jane (39) I*

This 'boredom' and 'loneliness' suggests that some respondents lacked the level of social interaction that they might have liked.

The need for staff support might have led to this lack of interaction and reliance on particular activities. Two interviewees spoke of the difficulties of getting out of the house outside of scheduled activities if staffing levels were low. If staff were not available, some of the respondents were unable to go out at all (an issue for respondents in Goble's 1999 study). Deborah, who has a physical impairment and uses a wheelchair, was particularly frustrated that she could not go out as often as she would have liked. Although she blamed this on her impairment, it was clear that her reliance on staff for help to get out was also a factor that she recognised. In the following quote,

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<sup>145</sup> In suggesting this, I do not wish to suggest that the users attended for these reasons alone. Responses to both the drop-in and the courses were mostly enthusiastic, and it was clear that the centre was actively chosen as an important place to be.

<sup>146</sup> A UK study that included interviews with five women and four men.



Deborah is initially talking about a small group home that she had previously lived in<sup>147</sup>. She then moves on to talk about the home she lived in at the time of interview:

*Deborah: I was sick of it, being indoors all the time. I wasn't doing a lot. All the time from getting up in the morning, from going to bed of a night-time. I wasn't...because I wanted to go to the shops, but they never took us.*

*Elizabeth: Right. So you asked?*

*Deborah: Yeah.*

*Elizabeth: And they didn't take you?*

*Deborah: No.*

*Elizabeth: When you are here, do you get out when you need to or when you want to?*

*Deborah: No. Sometimes I do, like. But not all the time.*

Deborah (46) **I**

Deborah directly linked staff shortages with constraints on her ability to go out. She also reported that 'I haven't got anything to do', suggesting that there were few activities to be involved in within the home.

Deborah's limitations were partly based on her use of a wheelchair. However, Julia, who did not use a wheelchair, felt that she was constrained by her lack of independence and her resulting dependence on staff to accompany her on trips, as she described here:

*That's the other thing, independent travel. I'm not allowed to get the bus.* Julia (25) **I**

Although Julia was able to go to her local shops on foot, she was not 'allowed' to travel by bus alone. Like many respondents, she was therefore dependent on taxis to get about, presumably because staff time could not be devoted to accompanying her on the bus<sup>148</sup>. Like Deborah, Julia commented that staffing levels were sometimes low, meaning that

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<sup>147</sup> Although Deborah was unable to tell me exactly when this was it would be likely to have been in the last six years (Deborah lived with her mother until she was in her forties and Deborah was forty-six at the time of interview).

<sup>148</sup> Which are more expensive, potentially limiting the money that Julia might have to spend on her social life.

she was not always able to go out when she wanted to. Jeanette, on the other hand, asserted her independence by going out alone<sup>149</sup>, as seen in the following quote:

*I don't like going with staff all the time. I prefer to go on my own. Because that [going out with staff] takes all my independence off me. Jeanette (50s) I*

It is clear that different degrees of dependence on staff affected respondents' activities – where they could go, and what they could do.

Restricted opportunities to socialise, particularly in relation to *where* they could socialise, impacted on some respondents' ability to maintain relationships over time. Julia, for example, reported having lost contact with friends on leaving college. Although she said that she would have liked to have seen friends, it appeared that her relationships with them were institutionally-bound: when one form of activity ended, the relationships associated with that activity ended also. As Julia pointed out, she now spent her daytime at the drop-in at the centre where the women's group met, but where none of her college friends went. Julia's lack of independence might have affected these friendships in that she was unable to visit them outside of the college social space without staff help to do so. Julia could not explain why she did not have the support to do this. None of the interviewees, including Julia, referred to the possibility of keeping in touch with friends via phone or letter. Additionally, and in common with other interviewees, Julia did not visit friends and was not visited by them, as seen in the following quotes:

*Elizabeth: You said that you don't see your college friends any more. Why don't you see your college friends any more?*

*Julia: I don't know.*

*Elizabeth: Were you able to see them outside of college?*

*Julia: Nah.*

*Elizabeth: Why not?*

*Julia: I don't know.*

*Julia (25) I<sup>2</sup>*

*Elizabeth: Do you have anybody visit you at home?*

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<sup>149</sup> However, Jeanette is 'allowed' to go out alone, whereas Julia is not. It is significant that Jeanette is able to do this as her life was significantly constrained during the years she spent in the local long-stay hospital.

*Julia:* No.  
*Elizabeth:* Just your parents and family (Julia had already indicated that they visited)?  
*Julia:* Yeah.  
 Julia (25) I<sup>2</sup>

Vicky also talked about not being visited by friends:

*Elizabeth:* Do you have friends that visit you here [Vicky's home]?  
*Vicky:* No  
*Elizabeth:* Do you ever visit friends in their houses  
*Vicky:* Yes  
*Elizabeth:* Could I ask where you met your friends?  
*Vicky:* Just through parents  
 Vicky (28) I

Although Vicky did visit these friends in *their* homes, they were friends that she had met through her parents, rather through interactions in other settings, suggesting that her social networks were nevertheless restricted<sup>150</sup>. Mary too had suggested that she only went on family visits, and stated that 'I've got friends, but not a really good friend.' Jean suggested that whilst she was not visited by friends, she met them during her visits to the drop-in at the organisation where the women's group met.

For other interviewees, sexual and intimate relationships were affected by the way in which these were institutionally-bound. Jane, for example, only spent time with her boyfriend at her day service work placement, and Deborah reported that she was also constrained in relation to where she could meet a previous, and only, boyfriend:

*Elizabeth:* So, do you see your boyfriend outside of your work?  
*Jane:* No, inside [the work placement].  
*Elizabeth:* Just there?  
*Jane:* Yes.  
*Elizabeth:* You've said you'd like to see him more outside, why don't you see him outside?  
*Jane:* I don't. I see him inside. He keeps popping in and saying 'Morning! Morning!'

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<sup>150</sup> It would be interesting in hindsight to have found out whether Vicky visited these friends with her parents.

*Elizabeth: But what stops you seeing him at other times? You said that you'd like to.*

*Jane: Yes, I'd like to, yes. So I could be with him and be getting a relationship with him.*

Jane (39) I

*Elizabeth: Were you able to meet?*

*Deborah: Just in the ambulance and that.*

*Elizabeth: Was that travelling to the day service?*

*Deborah: Yeah, the day service.*

*Elizabeth: Did you see him anywhere else?*

*Deborah: No, I don't see him now.*

*Elizabeth: Can you remember why you stopped seeing him?*

*Deborah: Because I live a long way now.*

*Elizabeth: You're not able to see him because of the distance?*

*Deborah: Yeah.*

Deborah (46) I

Jane's comments show that not only was her relationship restricted to a particular context, she also felt that being able to see her boyfriend outside of this context would make theirs a different kind of relationship. It was clear from what Jane reported that she would have liked to have seen her boyfriend more often. She also commented: 'I stay in at home all night', which seemed at odds with her desire to go out, and spend time with her boyfriend 'clubbing, or going out to cinemas.' This suggests perhaps that Jane's relationship was not necessarily taken seriously (Todd and Shearn 1997).

Deborah's comments show how her relationship was restricted to a very specific social space, and how when she moved home, this relationship ended. In actuality Deborah had moved within an easy travelling distance (within ten miles), and this further suggests that Deborah both lacked the independence to travel such a distance, and the support to do so. Deborah would have liked to have continued seeing her boyfriend and told me that she had not had boyfriends since. Finding suitable partners might also have been a difficulty, as Deborah suggested that 'I would have liked a boyfriend...if I'd had the chance', making the ending of this one relationship significant.

Anne too experienced the ending of a relationship because of a change in home. When I asked why she had split up from her only boyfriend she replied 'because I had shifted (moved).' When I asked why she could not get to see her boyfriend, since she too had not moved far, she replied that she did not know. Like Deborah, she reported that

she had missed her boyfriend and that she would have liked to have continued their relationship. Along with Liz's experience of having to delay moving in with her husband, these examples show a lack of provision, and even vision, by services to enable these women to maintain significant relationships or live 'normal' lives. Why this was the case, given that the aims underpinning services include the aim to support people with learning disabilities in all aspects of their lives, including their sexual lives, is unclear. I would suggest that there are a number of possible reasons, including a lack of consideration that women with learning disabilities can have or want intimate relationships and/or sex; lack of resources to support them; and lack of training so that staff feel confident to support people with learning disabilities in relation to their sexual lives (Christian *et al.* 2001, McConkey and Ryan 2001).

It is clear that respondents were in many ways unable to act in improvised, unplanned and informal ways, with relationships restricted to specific locations. As both Tøsseboro (2005) and Traustadóttir and Johnson (2005) have highlighted, people with learning disabilities are often limited to structured activities, and Bigby and Fyffe's (2006) empirical study found that community service provision did not allow for flexibility in relation to service users' day-to-day activities, which were related to set routines. The *Valuing People* White Paper recognises that people with learning disabilities have limited social circles, where 'time is spent only with family carers, or other people with learning disabilities' (Department of Health 2001a:1) and that 'many have few friends outside their families and those paid to care for them (Department of Health 2001a:14)<sup>151</sup>. Löfgren-Mårtenson (2004:201) suggests that the leisure time of the group she studied was 'often censured and characterised by strict boundaries...due in large part to so-called "created communions", which require others to organise and plan the activities in which one participates.' This might also be true for the respondents in this study, with these 'boundaries' and 'created communions' affecting who these respondents met and how they socialised, and arguably also affecting what they learnt about sexuality, who they might have met in relation to potential sexual partners and how they might have acted (or not) sexually. Although eleven respondents reported

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<sup>151</sup> According to this document only 30% of respondents in a survey conducted prior to its publication had a friend who did not also have a learning disability, and was not a part of their family or paid to care for them (Department of Health 2001a).

having had relationships with men, these relationships were most often formed within organised environments. It might be argued that constraints on the possibility of conducting sexual relationships, or constraints on those relationships that existed, also related to the failure of staff and services to expect and make provision for relationships: a lack of physical *and* emotional ‘space’<sup>152</sup>.

Looking more widely at the issue of staff support, and staff supporting clients’ sexuality, Brown (1994:128) suggests that:

...service workers have balked at actively supporting people in “ordinary” sexual roles, because...workers suspect that these “ordinary” roles are off limits. What is valued for others is greeted with fear, hostility and disapproval by members of the public when it is people with learning disabilities who want to engage in sexual activities.

Whilst support workers’ ‘balking’ at helping people to have ‘ordinary’ sexual roles might not necessarily mean that such roles are ‘off limits’, this point does highlight the difficulties support workers feel are associated with this aspect of their work. Whilst difficulties might be based on concerns about this group’s capability to have sex, relationships or children, or the risks to them should they experience any or all of these, Brown associates such difficulties with the ‘fear, hostility and disapproval’ of non-disabled people. She suggests that staff might not support people with learning disabilities’ sexuality because of the general disapproval by *others* in relation to this role (Parkes 2006). This disapproval might go deeper than fears around capability or safety, and are, perhaps, fears related to the ‘unintelligibility’ of people with learning disabilities leading sexual lives. Additionally, staff’s own attitudes might be at play here, for example Aunos and Feldman suggest that ‘more recent studies suggest that the majority of professionals maintain major concerns about marriage and parenting for persons with intellectual disabilities’ (2002:291) (the impact of gender was not discussed however, and reasons why staff might feel this way were not given). Christian *et al.* (2001) highlight the way in which staff are influential in the lives of people with

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<sup>152</sup> Lack of such space might explain why Mary for example attended the organisation where the women’s group met on days when her ex-husband (who had been violent towards her for ten years – the reason why Mary divorced him) attended also. It was unclear whether Mary had told anybody about this, but it was clearly problematic – from what she reported – for her to deal with.

learning disabilities. For example, their US study showed that staff's personal values and beliefs were more influential in the way they supported clients' sexuality than organisational policies. This may (as in Julia's case in this study) work against people with learning disabilities learning about or experiencing sexuality.

Later empirical studies suggest that in many cases services and staff *do* want to support people with learning disabilities to have sexual lives but face barriers in doing so, including lack of training, policy and guidance (see for example Christian *et al.* 2001, McConkey and Ryan 2001<sup>153</sup>).

## Conclusion

Forrester-Jones *et al.* (2002) found in their interview study of the quality of life of men and women with learning disabilities and mental health problems twelve years after resettlement from long-stay hospitals, that despite living in smaller houses in the community, respondents still desired greater independence, more opportunities to go out, and to have more opportunities for personal and sexual relationships.

In this chapter I examined issues of constraint and agency in relation to family and formal service practices. Firstly, I examined this in the family context, and highlighted the way in which some respondents had decisions made on their behalf by their families, before suggesting that these issues were exacerbated for some respondents in that they lived at home for longer periods than might be expected for other non-disabled groups. Secondly, I examined this in the residential services context, and looked at constraint in relation to choice over where residents lived, who they lived with, and decision-making in general. I concluded by looking at respondents' lack of scope and range in day-to-day activities.

This examination highlighted a number of significant issues, some of which were also evident in the previous chapter's analysis. These included issues in relation to decision-making, limitations on respondents' transition from child to adult status (with an accompanying lack of choices, lack of control over money, and lack of transition into

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<sup>153</sup> Research involved gaining data from 150 service staff (both men and women, and via questionnaire) within one community health and social services trust area in Northern Ireland.

employment, marriage or a long-term cohabiting partnership), and restrictions in relation to their social networks.

Further implications of these include a dependency on learning disability-specific activities, which are heavily supervised and subject to specific timetables, and friendships and intimate relationships dependent upon these. Movement outside of these timetabled activities was often dependent on staff availability. This relatively rigid structure precludes spur-of-the moment decisions and is reflected in the way in which many respondents relied on meeting up with friends *within* this structure, and rarely outside of it (for example not visiting each others' homes).

These restrictions appeared to exist for all the respondents regardless of age, a finding which might not be expected for non-disabled people. Younger respondents like Michelle, for example, who is one of the most independent of the respondents, complained about a limited social circle and boredom. Although it is difficult to detect whether or not gender played a part in these issues, it can be suggested that the notion of the need to protect women with learning disabilities, from sexuality for example,<sup>154</sup> might strengthen these respondents' experiences of constraint.

These constraints represent a potential impact on respondents' sexuality in a number of ways. A limited social circle and dependency on particular people represents more limited sources of sexual knowledge(s) and limitations on who respondents can meet, including potential sexual or intimate partners. Lack of privacy, social 'space', and agency therefore impacts upon how they can conduct their sexual lives. I would argue that more generally, a lack of consideration for this group's potential, as well as existing, sexual lives both undermines policy discourses of choice, rights and independence, and reflects older accounts and discourses of learning disability and asexuality and/or danger. I would further argue that these constraints, which sit alongside and reinforce the sexual accounts described in the previous chapter, contribute to the generally negative views of sexuality reported by respondents. In the next chapter I will look more closely at how the accounts and practices discussed in this and the last chapter, might be reflected in respondents' own views of sexuality.

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<sup>154</sup> This notion of protection might not necessarily be explicit.



## CHAPTER SIX

### **Women with Learning Disabilities: Accounts of Sexuality, Gender and Learning Disability**

#### **Introduction**

In the previous two chapters I suggested that institutional accounts of sexuality, and institutional practices, in relation to both families and professional services, might act as forms of regulation and constraint in relation to respondents' sexual lives. In this chapter I will focus on the key accounts and discourses on sexuality, gender and learning disability evident within respondents' descriptions of themselves, and their opinions in relation to sexuality, more generally. Much of this material reflects the accounts and discourses evident in family and service settings, suggesting that these might be influential on the way in which respondents give meaning to sexuality. The way in which individuals' attitudes and practices appear to be shaped within family settings in particular is confirmed in the wider 'mainstream' UK research by Hockey *et al.* (2002:3.1), who conducted six focus groups with heterosexual people of different ages, classes and sexes, to gain a sense of change over three generations in relation to the institution of heterosexuality. The authors argue that their research showed 'the existence of some striking family-based historical continuities', although there were also *discontinuities*.

I will begin this chapter by looking at the way in which normative accounts and discourses, that relate sex to marriage and parenthood, are reflected in many respondents' comments. I will then consider the way in which respondents frame sex in negative terms, and link sexuality to 'dirtiness', embarrassment and shame. I will move on to describe the ways in which sex, relationships, and having children were cast as 'unsafe'. I will then examine the way in which romance discourses, as well as companionship discourses, figured within narratives. I will go on to look at the way in which femininity was negotiated by respondents, arguing that seeing femininity, and gendered discourses in general as constraints, might obscure the way in which these might also act as a form of agency. Finally, I will return to the notion of 'difference',

arguing that a sense of their difference to others was apparent within respondents' accounts, and that this might reinforce the idea that a sexual life was 'not for them'.

### **Relationships, Marriage and Parenthood**

One amongst a number of themes emerging across the data was that of respondents encountering normative accounts and discourses of sex, relationships, marriage and parenthood, particularly within family settings. Respondents themselves appeared to slip from talking about sex to talking about relationships, marriage and children. This slippage occurred irrespective of age, and frequently took the form of what might be considered to be a moral discourse. This included the idea that sex should not take place before marriage, and that marriage should come before parenthood, as evidenced in the following quotes:

*You shouldn't have sex and not be married, the two [men and women]<sup>155</sup> should get married first. Jeanette (50s) I*

*Well, my brother, see when he got married, he's been married a long time, they had one, a little laddie, before they got married. But I don't think that it was right. I couldn't say anything to them, but I don't think it was right. Jean (66) I*

*Elizabeth: Do you think it's okay to have children and not be married?*  
*Michelle: I don't think it's nice.*  
Michelle (29) I

These moral discourses I argue, serve to act as forms of normative constraints, and are particularly significant when expressed by younger women, such as Michelle, given a changing context where such opinions are less pervasive (Wellings *et al.* 1994, Walby 1997)<sup>156</sup>.

When answering my question 'what does the word sex mean for you?', those interviewees that were able to answer talked of it in terms family, and of a seemingly

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<sup>155</sup> All respondents referred to sex in terms of two people, other than in relation to comments about masturbation. References to masturbation were only made by *Sex, Love and Relationships* participants, during my observation of the course.

<sup>156</sup> Haste (1994) has argued that whilst more liberal views of sexuality have emerged over the last century, there is, nevertheless, evidence that conservative moral viewpoints persist alongside these.

natural progression from meeting somebody, to marrying them, to having children, which can be seen in the following quotes:

*Elizabeth: This is quite a difficult question to answer, but what does the word 'sex' mean to you?*

*Jean: Well, just having sex like, to have a family to me.*

*Elizabeth: So it's more than a physical act –*

*Jean: That's what it's for, families.*

*Jean (66) I*

*I would call it [sex] trying to make friends, getting to know them [a partner] a bit better, moving on, getting married, and then getting kids. And sticking together through thick and thin. Sally (25) I*

*(Sex means to) live together, get engaged, get married, have kids. Susan (56) I*

This connection between sex and marriage was evident in Susan's description of her own experience of having a relationship. As suggested in the previous two chapters, Susan feared sex, and did not want it. Nevertheless, she got engaged to her boyfriend, but was adamant that she did not really want (and never had really wanted) to get married:

*I just wanted to be on my own, I just wanted to be engaged to him. I didn't want to get married to him. Susan (56) I*

Here, Susan appeared to be conflating marriage with being with someone more of the time than if she were single, of a loss of physical and/or emotional space, and engagement as something that would allow her to be on her own. This seems to reflect a normative discourse that might be particular to Susan's generation. She relates engagement with 'distance' from her fiancé, whereas marriage represents emotional and physical proximity, and perhaps, sex.

The language that respondents used also reflected normative notions of sexuality, particularly in terms of faithfulness and longevity, and especially in terms of marriage. For example Michelle, a younger woman said:

*I just want to get married and settle down. Michelle (29) I*

Katherine described marriage in terms of husband as 'life partner', and one *Sex, Love and Relationships* participant described the need to 'be faithful, be true' to both a partner or husband. These views on marriage and relationships, whilst reflecting normative discourses, are nevertheless on the wane within the general population. Wellings *et al.*'s (1994) research found, for example, that patterns in relationships were changing: partnerships for life were less frequent than previously noted. Respondents' views might also reflect particular gendered discourses where women are seen to be more likely to desire commitment and monogamy within relationships than men (Hollway 1984, Allatt 1996). This suggests that these women have taken up potentially constraining and regulating gendered and normative discourses in the development of their own views of sexuality that might be less likely to be held by the general population.

Single parenthood was also seen as less than ideal by four interviewees (six interviewees who were asked about this gave an opinion). Jean in particular felt strongly about this, as evidenced in the following quote:

*Well, I definitely think, a single person should think about getting married before they have, well two of them getting married, then the child's got a father. I definitely think that. Jean (66) I*

Jean suggested, in relation to the 'single person' she had described, that 'she could have been a young one', suggesting that she was talking about a young woman, rather than a young man, or single person of any age. Hockey and James (2003:58) have suggested that despite the rise in lone parenthood, 'dominant representations of family structure are still identifiably nuclear...' Here Jean genders the 'single parent' discourse, and relates it to irresponsibility and youth – a normative viewpoint flagged up by the conservative media (Laws 1996). Sally, who was younger, defended single parenthood, but only within certain contexts:

*Well my mum is technically a single mum. But you see her husband died. It's okay like that. It's okay if you've been in a relationship and that person abused you. Sally (25) I*

This implies that for this younger respondent, such normative discourses were influential. Some women also suggested, usually implicitly, that women were ‘naturally’ the primary carers of children, and that parenthood ‘naturally’ involved a man and a woman. Jean, for example, automatically talked about women when I asked her about being a single parent ‘*She* would need help...say they wanted a child, and the *mother* says “I’ll help...”’ (my emphasis). Julia and Katherine said the following:

*Elizabeth:*     *So if she was on her own [a mother] and she had a baby she’d need help?*

*Julia:*           *Aye! Aye! You see (she would have no) husband to work. She’d have to get some help wouldn’t she?*

Julia (25) I

*Women when they get married expect, if they can, to have children. Men are, they’re not fussy...whether they have children or not. Because they’re not nurturers. Women are.* Katherine (54) I

Here, in response to the question ‘how would a single mother be viewed by others’, Julia said that the mother might need help. When I asked her about this Julia went on to suggest that this help would come in the form a husband, who would ‘naturally’ work, implying that the mother would ‘naturally’ care for the child. Katherine more directly marked the nurturing instinct as gendered.

The prevalence of these normative, and relatively conservative, accounts is, apparently, reflected in research with other people with learning disabilities (Galea *et al.* 2004). The apparent lack of generational change in ideas and beliefs about sexuality suggests that respondents are firstly in close or regular contact with conservative normative discourses of sexuality, secondly that respondents have limited contact with counter-discourses to challenge these, and thirdly, that respondents are ‘adopting’ such discourses as their own. Counter-discourses found within the media (a number of respondents referred to sex and sexuality on television), or the *Sex, Love and Relationships* course (which included, for instance, references to same-sex relationships), did not ‘dislodge’ such normative opinions. Although there is nothing within the data to suggest that having been labelled and brought up as someone who has a learning disability explains such attitudes (both family attitudes and/or respondents’

attitudes), I would suggest that the *predominance* of such attitudes, and its reflection in the attitudes of the younger women, suggest that it might. One could also argue that the kinds of interactions that respondents could have had outside of family and services, and the range of accounts they might have encountered if they had access to these, were also limited.

Despite most women expressing normative views, Katherine was conspicuous in questioning some of the concepts underpinning normative beliefs about sexuality, particularly in relation to religion<sup>157</sup>. Whilst she appeared to accept some of the things that the Bible said, she also questioned them, as seen in the following quotes:

*The Bible says they [men] should treat their wives as the weaker vessel...you should be in subjection to your husband and that made it [her relationship with her husband] difficult. But how can you be in subjection to someone who is treating you like a parcel, like a possession, do you understand what I mean?* Katherine (54) I<sup>2</sup>

*As it [the Bible] says, the husbands are heads of the household, there's no denying it because Adam was created first, so the husbands are really the heads. But at the same time the woman isn't an inferior person. If they're equal, they're exactly the same in God's eyes. We're not inferior beings, you know.* Katherine (54) I<sup>2</sup>

In Katherine's relationship with her husband it is important to note that although Katherine had 'chosen' to marry him, partly through lack of choice (she had had no other men approach her), she also felt comforted that he was a member of the Christian church, as she was. However, as she suggested, this 'hid' who he 'really' was<sup>158</sup>. Katherine's 'traditional' values, as well as her 'trust' in her husband, effectively placed her in an abusive situation. Despite this however, Katherine was one of two married women who ended their married relationships on the basis that they were being abused. Katherine ended hers after four years, and Mary after ten. Despite holding normative views of marriage and life-partnership, these women acted against these in extreme circumstances. This is an important example of how, despite respondents' apparent lack

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<sup>157</sup> Katherine herself had a strong belief in the Bible and its religious values, although in many ways she also questioned them, as seen here.

<sup>158</sup> Her husband was physically and mentally abusive.

of agency within particular contexts, agency was nevertheless exercised. Although Katherine did not refer to receiving help to do this, Mary said that she had help from the manager of the home she moved into after leaving her husband. This suggests that despite some interviewees' suggestions that they had few people to talk to about their abusive experiences, Mary, in this instance, received practical support at least.

Thus, most respondents' accounts reflected (hetero)normative discourses. In addition there was a fairly even split between those interviewees who felt comfortable with the idea that people could have same-sex sexual relationships (six) and those who did not (five). Of the remaining interviewees, the subject was either not brought up in interviews, or interviewees were unable to give an opinion. Whilst the number of respondents feeling uncomfortable with same-sex relationship was not necessarily high (McCarthy, 1999, found that thirteen of her seventeen female respondents, for example, held negative views of same-sex relationships), the strength of their opinions in relation to these was striking, as seen in the following examples:

*I think it's disgusting...a disgrace...why are they doing it? Dorothy (60) I*

*Elizabeth: Do you think it's okay for women to fancy one another, or be together?*

*Anne: No, I think it's stupid.*

*Elizabeth: Why's it stupid?*

*Anne: Well, it's a man to a woman or a woman to a man.*

*Anne (55) I*

Although these attitudes were more apparent in the older group of respondents, younger women too, including Jane at thirty-nine and Julia at twenty-five, also described how they felt that these kinds of relationships were wrong. Similarly, Wellings *et al.*'s (1994) research found that younger respondents were not significantly more tolerant than older respondents. Respondents in this study did not necessarily distinguish between men and women in terms of their 'acceptance' of same-sex lifestyles, although again, the strength of three of the respondents' responses indicated that they had greater difficulties with

women having same-sex relationships<sup>159</sup>. Although why this was the case was not clear, one respondent's response was so strong that it indicated that she might have been approached sexually by another woman, as suggested by the following quote:

*Elizabeth:* Has anybody talked to you about girls being together like that [I show Jane a line drawing of two women hugging/kissing]?  
*Jane:* [Quite forcefully] No, I don't like girls at all.  
*Elizabeth:* No, you don't?  
*Jane:* No, I don't. (Because) I don't kiss women at all. Just kissing a man, that's all.  
*Elizabeth:* And that's the way you feel?  
*Jane:* Yes.  
*Elizabeth:* What about other people, if they chose to? If it wasn't anything to do with you? How would you feel?  
*Jane:* I'd get angry about that.  
Jane (39) I

Many respondents' comments also suggested that sex was seen in terms of biological 'need' and an essentially procreative act. Wellings *et al.* (1994) have shown that there is a continued intolerance towards same-sex relationships, and that those who hold normative values regarding sex and marriage also hold less tolerant attitudes towards same-sex relationships. As Katherine suggests; 'the sex act itself should be reserved for marriage, because it's a means of procreation, and it's a gift.' Normative notions of sexuality might therefore have been reflected in respondents' negative views of same-sex relationships.

What is particularly interesting in relation to these women's attitudes is that most denied that parents or carers felt similarly. As Dorothy said about her family: 'they don't bother.' Women in the focus group, as well as Susan, an interviewee, referred to the media when talking about same sex relationships. The focus group discussion centred on television 'soaps', which were used to illustrate participants' knowledge of lesbian and gay relationships. However, it was not clear whether the negative attitudes expressed by respondents generally were also linked to negative depictions of such relationships on television. Since depictions in the media appear to be increasingly 'positive' in relation

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<sup>159</sup> Wheeler's (2007) admittedly small-scale research shows that his respondents (*men* with learning disabilities) also had more difficulties accepting lesbian relationships.



to same-sex relationships (Plummer 1995), it seems odd that these women appeared to hold such strong beliefs. Similarly, attendance on the *Sex, Love and Relationships* course did not seem to alter these respondents' opinions.

Negative attitudes in relation to same-sex relationships seemed to have been influenced by more diffuse means; by a more general societal negativity towards non-heterosexual relationships<sup>160</sup>. This lack of awareness or clear knowledge of the sources of these attitudes is exemplified in the following quote:

*Elizabeth:*      *Why do you think that [being a lesbian] is stupid?*  
*Anne:*            *I don't know, I just think it is, that's why.*  
Anne (55) I

I would suggest that this statement reflects a difficulty for respondents in fitting same-sex relationships into their understanding of what sex is (for example, procreative), as suggested by Anne's comment that relationships were composed of 'a man to a woman or a woman to a man.' This difficulty is also seen in the following examples, where there is a sense that respondents are trying to reinforce what they consider to be the 'right' way to conduct relationships, or attempting to 'bring' same-sex relationships 'back into' a framework they understand or are familiar with:

*They [women/lesbians] should have a boyfriend.* Jeanette (50s) I

*Men don't kiss each other. He kisses a girl, not a man.* Jane (39) I

If legitimate sex is seen as part of a 'trajectory' that involves two people that meet, who like or love each other, who then get married (before having sex), and who then go on to have children, other ways of living, of having relationships and of having families, might be difficult to imagine, or to see as 'intelligible' sexual options. If, in addition, sex is only seen as legitimate in heterosexual relationships, choices are further reduced. Although none of the respondents reported having heard the staff who worked with them expressing negative attitudes towards same-sex relationships, Brown (1994)

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<sup>160</sup> This vagueness of the origins of particularly strong moral opinions was specific to opinions on same-sex relationships. Other attitudes, such as those about sex before marriage, or marriage before parenthood, could be traced more directly to family.

and Clements *et al.* (1995) suggest that services in relation to people with learning disabilities, alongside other kinds of institutions (Carabine 1996a, 1996b, Jackson 1996b), tend to be heteronormative. A heteronormative atmosphere both reduces the possibility of learning about same-sex relationships or having same-sex relationships and makes those relationships less legitimate.

### **‘When Somebody’s Talking To Me About Sex, I Don’t Like It’:**

#### **Negative Accounts of (Hetero)sexuality**

Sexuality was more or less consistently described in negative terms, apart from by a small but significant handful of women (which I will focus on in later sections of this chapter). As suggested in Chapter Four, respondents suggested that sexuality tended not to be discussed in family and residential institutional settings. I argued, however, that such ‘silences’ are productive (Foucault 1990), and that despite respondents’ perceptions of a ‘silence’, sexuality was in fact discussed in normative and sometimes negative terms within family and institutional settings.

As already suggested in Chapter Three, many women simply ‘shut down’ when asked about sexuality. Mary, for example, became very quiet and monosyllabic when I began to ask her about sex, and Suzanne became too upset to talk when I asked her about sex, boyfriends and having children. In both cases it was difficult to get information from the women, and with Suzanne the interview was terminated. Part of this interview is replicated here:

*Elizabeth:*      *Could I ask if you’ve got a boyfriend*  
*Suzanne:*        *[Shakes head.]*  
*Elizabeth:*      *You haven’t got a boyfriend?*  
*Suzanne:*        *[Shakes head.]*  
*Elizabeth:*      *Would you like a boyfriend?*  
*Suzanne:*        *[Shakes head.]*  
*Elizabeth:*      *Why wouldn’t you like a boyfriend?*  
*Suzanne:*        *I don’t like it [whispers].*  
*Elizabeth:*      *What wouldn’t you like about having a boyfriend?*  
*Suzanne:*        *I don’t like it.*  
Suzanne (40s) **I**

This interview continued in a similar way when I asked her how she felt about marriage and having children. Suzanne became tearful and increasingly withdrawn, and I ended the interview. It was never clear why Suzanne found talking about these things so uncomfortable, or indeed why other respondents did. Although I was asking some respondents about sex, and it might be expected that they might find this difficult to talk about, it was also unclear why some respondents found it difficult to talk about the 'easier' subject of relationships. Whilst some respondents had had difficult experiences of sex and relationships, and whilst sex is a 'difficult' subject, I would suggest the possibility that talking about something you have never experienced and might never experience makes it particularly difficult. Further, those women from older generations might find these subjects, particularly sex, additionally difficult to talk about, given the less liberal attitudes towards sex within previous generations (Haste 1994).

Some women were explicit about not wanting to talk about sex, as seen in the following examples:

*Jean: I wouldn't talk to anybody about sex*  
*Margaret: I don't like talking about it*  
*Jean: When somebody's talking to me about sex I don't like it.*  
*Margaret: I don't like to talk about it.*  
 Jean (66) and Margaret (60s) **FG**

*I'd walk away, (because) they're talking to me.* Barbara (40s) **FG**

In part, these respondents' reactions to discussions about sex might be related to a lack of interest in them. However, responses to questions about sex were often severe, as seen in Barbara's comment: 'I'd walk away.' This lack of desire to engage in discussions about sex could, on the one hand, be a product of respondents' discomfort with the notion of sex, but it could also be due to a lack of knowledge about sex. For example, some women were not knowledgeable and may have wanted to avoid making that lack of knowledge known.

Despite this 'silence', respondents did talk about sex and relationships, although most often negatively. This view supports McCarthy's (1999) findings, where nine out of her seventeen respondents spoke negatively about sex. The major reasons given for

this included the physical pain that some experienced (six women said that sex *always* hurt them), and the way in which their partners sometimes treated them ‘roughly’. As already highlighted, many respondents in this study suggested that they did not want relationships, a finding that reinforces the findings from Heyman and Huckle’s (1995) small-scale study, where seven out of ten of their female interviewees rejected the idea of a sexual relationship (a much higher figure than that for the male interviewees). Five of the interviewees in this study, aged between twenty-five and sixty-six, had never had a relationship, and said that they did not want one. Two women, aged fifty-four and fifty-five, who had had partners/sexual relationships suggested that they were now ‘too old’ for them. A further four, all aged in their fifties and above, who had experienced sexual/intimate relationships, suggested that they did not want another one at the time of interview: all reported having had abusive experiences in relation to men and/or relationships. A further interviewee, aged twenty-eight, was reluctant to have a relationship, because her previous experiences showed that men ‘two-timed you.’ This lack of desire for a relationship is particularly evident in the following exchange with Julia:

*Elizabeth:*     *Do you think that there would be anything good about having a boyfriend?*  
*Julia:*           *No.*  
*Elizabeth:*     *Nothing good?*  
*Julia:*           *No, I don’t want one [getting irritated].*  
 Julia (25) I<sup>2</sup>

In a continuation of this exchange Julia stated (as discussed earlier) that she was not allowed a relationship, and appeared unable or unwilling see beyond this, or imagine a different scenario, where she *could* have a relationship. Whether or not Julia was so constrained by the prohibitions on her having relationships, as discussed earlier, that she could not think beyond them, or whether these prohibitions *allowed* her not to think beyond them is unclear.

I would suggest that there might be a number of interconnecting and complex reasons why respondents might not want sex or relationships, as discussed throughout these data analysis chapters. These, I would argue, include not being seen as sexual and

constituted as such, being protected against sexual contact (so that sex is seen as dangerous), and being subject to practices that make being sexual difficult (for example not having the physical and emotional space in which to have relationships). I would suggest, therefore, that many of these respondents did not ‘learn’ about sex or desire, or ‘learn’ that sex and desire could be a valid part of their lives. In Gagnon and Simon’s (1974) terms, they did not have access to the ‘script’ that taught them what these things were, or that they were things that they could ‘have’.

This is compounded perhaps by the gendered notion that, historically, women are not supposed to desire sex (Haste 1994), which might have had particular impacts on respondents from older generations, who would have been more likely to have encountered such discourses. As Jean pointed out in this study: ‘Well some (women) don’t like it, do they, really?’ This attitude is reflected in Millard’s study where some of the women she spoke to did not believe that they had a right to sexual pleasure. As one woman said: ‘most women don’t enjoy sex, we’re just being used’ (although this respondent’s experiences of abuse no doubt contributed to her point of view). McCarthy’s (1999) research also found respondents failing to relate sex with pleasure or desire. Desire perhaps represents a flip side to asexuality, with learning disability more usually associated with the latter. This ‘missing discourse of desire’ therefore, might be associated with both gender *and* learning disability.

During my observation of the *Sex, Love and Relationships* course, when the men and women split into separate groups to discuss ‘what is sex’, women’s descriptions mentioned neither love nor desire and at no point was sex described as positive. Neither men nor women described sex in terms of orgasm, but the men’s responses to the question ‘what is sex’ were more nuanced than the women’s, included responses that linked sex with pleasure, and included references to a range of sexual acts including flirting, touching and kissing (see Appendix Twelve).

This sense that love and desire, as well as sex, were not a feature of female respondents’ lives, was encapsulated by Sally in the following quote:

*I don’t think she would be happy with me spending time talking about sex on the phone with her. Sally (25) I*

Although Sally did not detail precisely why she thought her friend would not like her talking about sex, her own attitude towards sexuality, and particularly love, throughout the interview, suggested that these were not important subjects, and that she would be wasting her friend's time by talking about them (rather than, for example, because her friend or herself would be *embarrassed* to talk about sex – Sally was one of the few respondents who seemed relatively comfortable talking about this subject).

When I asked interviewees whether they did, or had felt 'sexy', almost overwhelmingly they replied that they did not feel sexy (or had not felt sexy), with a few simply answering with a point blank 'no', which can be seen for example in the following exchange with Jean:

*Elizabeth:*    *Is there anything that makes you feel sexy, as a person?*  
*Jean:*           *No, never.*  
*Elizabeth:*    *No? Not like clothes?*  
*Jean:*           *No.*  
*Elizabeth:*    *Watching anything?*  
*Jean:*           *I don't fancy anything like that.*  
*Elizabeth:*    *No. So you wouldn't say you feel sexy?*  
*Jean:*           *No.*  
Jean (66) I

This commonly expressed 'lack' in relation to 'feeling sexy' is, I would argue, particularly important. It suggests that some respondents have little or no sense of themselves as sexual beings, or as potential sexual beings or agents. This potentiality, it could be argued, forms a precursor to embarking on a sexual life: in order to be a sexual agent, one needs to feel oneself to be sexual, or to have a sexuality.

The way in which sex was viewed by respondents, and the way in which this impacted on their avoidance of relationships, particularly after 'difficult' experiences, has already been documented in this thesis. However, despite a generally negative attitude towards sex and relationships reflected across respondents' accounts, there was also evidence that some felt positively, or felt positively about particular aspects these. Deborah and Jeanette talked about being close to others, as seen in the following exchanges:

*Elizabeth:* What was it about him [boyfriend] that made you fancy him?  
*Deborah:* It was the way he went on.  
*Elizabeth:* Yeah? In what way?  
*Deborah:* Like putting his arms around us.  
*Elizabeth:* You liked that?  
*Deborah:* Yeah.  
Deborah (46) I

*Elizabeth:* Did you like being cuddled for example?  
*Jeanette:* Yes, being hugged and cuddled, but I don't like kissing.  
Jeanette (50s) I

Others talked about feelings. For example, Sally, who said that she did not want sex or a relationship, and who tended to see sex and relationships as unsafe, did suggest, when I asked her about lesbian and gay marriage, that 'everyone deserves happiness whether you are gay or not.' Although this seems to be a statement about the equal rights of lesbian and gay people, it illustrates that although Sally did not see sex or relationships as positive choices for her, she could see that *for others* sex and relationships could lead to happiness. Liz frequently used the word 'nice' in response to questions about her husband. In addition, her body language changed when she talked about her husband, and she giggled. It was clear that she both loved and 'fancied' her husband, and had done so – according to her – from the day she met him.

Jane was particularly happy with the sexual aspect of the relationship she had with her boyfriend:

*Elizabeth:* How do you feel when you look at your boyfriend?  
*Jane:* You feel...you feel like having sex.  
Jane (39) I

*Elizabeth:* What kinds of things make you feel sexy, that make you feel good about yourself?  
*Jane:* You shut the door, and lock the door. That bedroom is private. And taking clothes off. And having sex and went to bed together. Like kissing and cuddling behind the neck.  
*Elizabeth:* Did that make you feel sexy?  
*Jane:* Yes.  
Jane (39) I

Here, Jane talked about how she felt good in relation to sex. These kinds of comments in relation to sexuality were, however, in contrast to the more dominant ‘negative’ views found in the data, which I will return to here.

### **‘It Might Be Rude’: Sex as ‘Dirty’ and Embarrassing**

One of the most striking associations to be made by respondents in relation to sexuality was that it was ‘dirty’, ‘disgraceful’ or ‘wrong’. Previous research has shown that people with learning disabilities have associated sex with it being ‘dirty’. For instance, Millard (1994) found that women’s group members focusing on sexuality felt that the sexual parts of their bodies were ‘dirty’, and Heyman and Huckle (1995) found that their respondents related sex to it being ‘rude’. Heyman and Huckle relate such attitudes to the way people with learning disabilities are not seen as sexual, and are not provided with sex education (although this argument fails to explain why sex is then *necessarily* seen as ‘dirty’).

In this study, Deborah in particular made an association between sex and ‘dirtiness’ and tellingly, her mother had made this connection when Deborah had mentioned it as a child. In the following example Deborah explained that sex was discussed (as a formal and informal topic) at the day centre she attended:

*Well they talk about it nearly every week (at the day centre)...I’m sorry but I don’t like that...I just don’t like a lot of fuss about that, the dirty things what they’ve done. Deborah (46) I*

Deborah was clear therefore that sex was ‘dirty’, also suggesting that she did not like a lot of ‘fuss’ – that she did not like sex being made into a ‘big deal’ perhaps, and certainly as a subject of conversation, much like the case of Sally, described previously. Additionally, Deborah appeared to try and avoid using the word ‘sex’, using ‘it’, and ‘that’. When I asked Deborah what might be ‘dirty’ about sex, she replied ‘well, having a lad’s leg in front of your leg.’ This, as well as illustrating the way in which she might be avoiding explicit description, also underlines the way in which she was either not fully knowledgeable about sexual matters, or that she could not find the language to



describe them. This possible ‘lack’ of language may be attributed to two different things: she either did not *know* what words to use because she had never been told them or, like non-disabled people, she felt uncomfortable with using particular (‘dirty’) words. This ‘lack’ of language is particularly evident when referring to women’s sexual anatomy (Lees 1993, Millard 1994).

Jean had a similar viewpoint to Deborah’s and again she linked that to her family’s opinions. In Chapter Four, I described how Jean thought that watching sex on television was a ‘bad’ thing, and that this was related to how her family would consider Jean watching sex on television as a ‘disgrace’. Jean also saw sex as something that should not be in magazines, as seen in the following example:

- Elizabeth:*     *What kinds of information on sex and relationships are there in books and magazines?*
- Jean:*           *A lot of things that shouldn’t be in!*<sup>161</sup>
- Elizabeth:*     *Like?*
- Jean:*           *I don’t read them sort of things, see.*
- Elizabeth:*     *Why not, I’m not suggesting that you should, but why do you, personally, not bother with that kind of thing?*
- Jean:*           *I don’t know really, for all I’ve been on the [‘Sex, Love and Relationships’ course]...I don’t even watch them on telly. It’s funny really.*

Jean (66) I

In relation to watching sex on television, Jean reported that her family thought that watching sex on television was ‘disgraceful’. Jean herself said that she did not want to watch sex on television, or read about it, as seen in the above quote. She highlighted that despite attending the *Sex, Love and Relationships* course (she also acted as a volunteer planner on it), she still felt the same. As suggested previously, this suggests that the *Sex, Love and Relationships* course does not necessarily change people’s attitudes towards sex, or at least some of the attitudes that they hold. Whilst Jean believed in the importance of the *Sex, Love and Relationships* course, she also held strong, normative views on sexuality, that seem at odds with the more liberal messages the course reflects. It is interesting that Jean herself could identify that, despite her involvement with the

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<sup>161</sup> Although Jean did not refer explicitly to ‘sex’ or specific sexual acts here, within the context of the discussion it was clear that she was referring to physical sexual acts.

course, her own opinions did not change. It is notable too, that Jean, who had been heavily involved in running the *Sex, Love and Relationships* course, had not told her family she was involved with it, suggesting that despite its role in giving practical advice to people with learning disabilities, its subject matter was still ‘difficult’ for her to talk about with family members who described sex on television as ‘disgraceful’.

Another aspect of sexuality that was frequently referred to was its embarrassing nature<sup>162</sup>. Although it was clear that respondents were embarrassed in relation to talking about sexuality generally, as was clear when talking with them, embarrassment was often related to discussing sexuality with, or in front of, men. During the *Sex, Love and Relationships* observation, for example, it was clear that the women felt more comfortable discussing sex when they were divided from the men. When the two groups joined back together, although both men and women seemed comfortable with feeding back their answers, when asked if the men wanted to ask the women anything or the women to ask the men, the group became quieter and comments more stilted. An extract from my fieldnotes, after the first such session, where participants explored how they felt when they ‘fancied’ someone, is included here:

When the women were asked if they had any questions for the men there was a silence, and when the men were asked if they had any questions for the women ‘John’ suggested that there were things he couldn’t share: he couldn’t be asked ‘about that.’

Exceptions included some of the comments made by one female participant (who seemed more comfortable with others as the course progressed), and some of the contributions made at the end where the facilitators asked the participants to reflect on course content and what they had learnt (again, there was a sense that the group had learnt to feel comfortable with one another).

The use of mixed groups, and her embarrassment about talking about sexuality deterred Julia from going on the *Sex, Love and Relationships* course, and was an issue for Jeanette too, although she decided to attend:

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<sup>162</sup> However, female participants on the *Sex, Love and Relationships* course – as observed by myself – did not mention embarrassment as something they related sex to, whereas male participants did. Despite this it is impossible to infer from this that embarrassment was not an important factor for the women on the course, as they were not asked explicitly about it.

*I don't want to do it... 'cause there's men and women together. Julia (25) I*

*Yes, I've been once on the 'Sex, Love and Relationships' course...I felt embarrassed about it but it was alright. Jeanette (50s) I*

Despite this, the *Sex, Love and Relationships* course was cited by respondents as playing an important role in learning about sexuality. It was also considered by some to be a 'safe space' in which to talk about sexuality, as already highlighted. The provision of a women-only version of the course, and the splitting of men and women into separate discussion groups, reflects the way in which men and women are perceived to be 'different', and have different needs. It might also be associated with an assumption that there will be a discomfort between men and women when sharing information on sexuality.

Other women highlighted the difficulties of talking to men about relationships and sexuality. Michelle had previously been in a relationship and still felt emotionally attached to her ex-boyfriend. Furthermore, she had been physically abused by this man, and had suggested that her family were not just tired of her talking about her love for him, they were also tired of her talking about the abuse. Michelle suggested that she needed to talk about her experiences, but nobody wanted to listen. She also commented that her social worker had been difficult to contact, and although she did not explicitly state that she could *not* talk to her key-worker, given her embarrassment about talking about sexual matters with (and in the same room as) men, this might have made it additionally difficult. This situation might have been something that a female key-worker would have been better equipped to deal with, as well as a more likely person for Michelle to feel comfortable talking to. Furthermore, since she had not talked to her key-worker in depth about what had happened to her, information about potential support in relation to her experiences had apparently not been given.

As suggested earlier, other respondents who had experienced physical and sexual abuse expressed a similar need to talk about their experiences, and of not having had any specialist help. Of these women Jeanette, in particular, suggested that her embarrassment

in relation to a sexual attack compounded her difficulties in talking to people that she knew and was close to, as seen in the following exchange:

*Jeanette:* I don't want to talk about it.  
*Elizabeth:* How did it make you feel?  
*Jeanette:* Awful about it, embarrassed  
*Elizabeth:* Would you have felt better if you could have talked about it?  
*Jeanette:* I would have felt better if I could have talked about it and all<sup>163</sup>  
*Elizabeth:* Was there any body that you did talk to?  
*Jeanette:* I talked to the police.  
*Elizabeth:* Did you talk to any of the staff?  
*Jeanette:* No, just to the police.  
*Elizabeth:* Any friends? Where you able to talk to them?  
*Jeanette:* They don't want to talk about it either, what I went through and that.  
*Elizabeth:* They didn't want to talk about it?  
*Jeanette:* No.  
*Elizabeth:* Did you try to talk to them about it?  
*Jeanette:* I tried to talk to them about it. I don't talk to them about it because I might upset them.  
*Elizabeth:* It might upset the person you were talking to?  
*Jeanette:* Yes. It might be rude. I might get myself embarrassed.  
*Elizabeth:* Does it help though, to be able to –  
*Jeanette:* Yes, it helps me to be able to, yes.  
Jeanette (50s) I

In this example, Jeanette was unable to talk about her experiences, and conflated sex with being 'rude' and 'embarrassing'. Although a violent act had taken place, which was not her fault, Jeanette could not talk about it because it was about sex. Furthermore, Jeanette suggested that her family did not talk about the assault, underlining the sense in which it might be her fault, and that sex is 'wrong' more generally. This points (as with Michelle) to the need to talk to a professional, who would be unrelated to her, and paid to listen, and who would be unlikely to get upset because Jeanette is a friend or family member. Jeanette said later in this interview that she might not have felt embarrassed about talking about sex if she had not been raped. Her reference to talking about the rape as being rude, does, however, suggest an existing awareness of sex as an embarrassing subject.

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<sup>163</sup> Jeanette could be paraphrasing me here, but given the way in which she answered other questions, and her assertiveness throughout the interview, I would suggest that this was not the case.

Charlotte talked about sex in terms of shame. Charlotte had hidden her husband's abusive behaviour from her sons, and only spoke about her experiences after her husband's death, after thirty years of marriage. As suggested in Chapter Four, her husband was able to manipulate her on the basis of the shame and embarrassment she felt over having also had an unwanted sexual relationship with her brother as a teenager; he threatened to tell other people of this event. This compounded the sense of shame that Charlotte already felt, who believed herself in some ways responsible for the way in which she had been treated. Charlotte described this in terms of the sexual acts her husband had coerced her into performing, as seen in the following quote:

*I feel ashamed of my life. I feel ashamed of the things I've done. I feel really ashamed. If I could, if I could turn the clock back, I wouldn't have done things...I couldn't even talk to my own mother about what was going on [with her husband]. Maybe I felt people would have said 'oh well, it's your fault, for getting married.'* Charlotte (56) **I**

As with the embarrassment expressed by Jeanette, the feelings of shame Charlotte associated with her experiences effectively silenced her, giving her no-one to share her feelings with and no support. Charlotte found it difficult to talk of, or express, her own desire to be touched; suggesting that she thought that what she would say might somehow offend me:

*I hope I'm not going to offend you with what I'm going to say, but when my husband, when me husband was here, I used to, he used to, I used to like being, how can I say it [Charlotte was evidently finding this particularly difficult to say], I used to like being touched, down below.*  
Charlotte (56) **I**

Although Charlotte had feelings of sexual desire, she evidently found it difficult to talk about this, underlining the difficulties some women feel in expressing a positive discourse of desire (Fine 1988, Tepper 2000), difficulties that might also be related to generational factors, given Charlotte's age (Haste 1994).

## **‘Unsafe’ Sex, Sexuality and Relationships**

*If he wants to have sex with me, then it’s probably going to be a bit scary.* Susan (56) I

Just over half of the interviewees overtly referred to their own and others’ general and specific sexual safety. Where women described situations in which they had been threatened sexually (not necessarily referring to their safety explicitly), the figure of those rose to eleven. Safety was not necessarily *explicitly* linked to learning disability (although sometimes it was), but despite this, references were made frequently enough, and without reference to questions about this (it was not something I explicitly asked about), to make it significant. More importantly perhaps, it was often the first or only aspect of sex that the women spoke about. Six interviewees described having had experiences of physical and/or sexual abuse. Three others had been in what they described as threatening situations. Two interviewees referred to the emotional trauma relationships could bring. Others seemed to *assume* that having sex, or being in relationship, would be a negative experience. This was expressed by what they said and by particular words that they used – sex was ‘bad’, ‘awful’, ‘scary’ or ‘terrifying’ but rarely ‘good’.

As suggested, many women tended to think that some life situations were dangerous. Susan for example considered her general safety to the point that she appeared to be heavily constrained, and constrained not by others, but by her fears. She was concerned about cooking at home (and refused to consider the idea that she could live on her own, or move out from the home she shared with her ex-fiancé and others – despite not wanting their company) and she was scared to go out alone (there was danger on the streets; a woman was killed; she would get lost). She constructed staff as ‘different’ to herself, and the people she lived with (staff were safe<sup>164</sup>, staff were safer than her on the streets; but she was not safe, and was not safe with other residents on the streets). This strong discourse related to safety is interconnected with discourses of disability, dependency and capability. Susan saw herself as less capable than others, saw

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<sup>164</sup> Although for some people with learning disabilities they were considered *unsafe* – Jeanette for example reported having been physically attacked by staff.

others as safer than her, and for both these reasons she could depend on them (rather than herself) for her safety. This fear and dependency clearly limited what Susan was capable of doing and the choices that she made on a day-to-day basis.

*Elizabeth:*     *Would you like to live anywhere else?*  
*Susan:*        *No, just like living here.*  
*Elizabeth:*    *What about living on your own?*  
*Susan:*        *I'd be just frightened on my own.*  
*Elizabeth:*    *What would make you frightened?*  
*Susan:*        *If I was doing anything wrong and I was living on my own.*  
                  *Cookers. Living on my own and using a cooker. I would just get*  
                  *burnt. There's got to be staff there.*

Susan (56) I

*I just say, I'd just be frightened (to go out) on my own. So I'd sooner just stay in the house.* Susan (56) I

It appears that, for whatever reason<sup>165</sup>, Susan had invested in the notion that she was more 'vulnerable' than others (staff in particular), and regulated herself in a way that restricted her privacy (she would not live outside of a service setting, which would give her more opportunities to have 'private' relationships), and her social interaction (she feared to go out, and was reliant on staff to do so). Hendey and Pascall's (1998) UK research with forty-two physically impaired young adults aged between seventeen and thirty-one showed that the young women interviewed, in particular, lived heavily constrained lives due to fears in relation to their safety, and their fear of potential violence, particularly in relation to men. These respondents were further constrained by parental fears in relation to the women's perceived vulnerability. Heyman and Huckle (1995) also found that their respondents who had learning disabilities were fearful of everyday hazards, such as cookers and knives; going out alone; and of getting robbed or attacked. They found that more particular fears in relation to sexual safety, and being able to cope with relationships, marriage and parenthood, were situated within this more general perception that life was hazardous.

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<sup>165</sup> Hollway (1984), for example, suggests that some women invest in subject positions that provide them with protection by others, and which reduce their responsibility for themselves.

Like other respondents, Susan's fears extended to include sex, relationships and parenthood.

*I think it's worse for a woman to have sex*<sup>166</sup>. Susan (56) I

*I wouldn't get married and I wouldn't have kids, it would be safer for me.* Susan (56) I

Susan, who had experienced a sexual assault as already indicated, had very particular fears surrounding sex and having relationships, including the pain of having penetrative sex, the pain of childbirth, being able to cope independently (this was also associated with marriage where she appeared to believe that she would have particular responsibilities that she would be unable to perform safely), and the fear of not being able to cope with a child. Here Susan gendered her fears by suggesting that it was 'worse' for a woman to have sex, reflecting discourses that suggest that women do not, or should not, enjoy sex. Sex is something that women either like less than men or it is something they endure. Susan was unable to accept the idea that sex could be pleasurable when I suggested to her that it might be. This perhaps reflects McCarthy's (1999) research findings where some of the women in her study said that they thought that sex was *meant* to hurt women. As suggested earlier, Susan linked marriage with sex, and whilst she had at one time been engaged, was reluctant to get married. Whilst she had had a boyfriend, she did not necessarily see having one as 'safe' however. Susan had suggested for example that 'I want to be single, safe.' Interestingly, Susan felt it was 'safe' to 'fancy' men and flirt with them – she had talked comfortably about how she flirted with policemen and sailors saying 'I wasn't frightened of them.' This suggests perhaps that expressing her sexuality through flirting was 'distanced' enough to avoid risk. Although Susan did not expand on why policemen or sailors might be 'safe', she did define them as potentially 'proper' boyfriends, marking them as 'different' to her ex-fiancé, a point I will elaborate on later in this chapter.

Other respondents also related their fears to things that had happened to them. Jean, for example, related to three instances where she had felt fear in relation to men.

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<sup>166</sup> Susan was referring to how enjoyable, or not, sex was. Within this context she meant painful and scary.



These events included an incident in a park (although it was not clear exactly what happened, Jean appeared to have been propositioned by a married man that she knew) stating: 'I was really terrified of him!'; an incident where she was grabbed around the neck by a boy who was with a group of other boys outside a shop, and a third incident that Jean described in the following way:

*When mum was ill, all I was getting was phone calls off lads [men], 'I know you, I went to school with you' and he didn't, he was just a stranger but it was the same lad all the time...it was terrible because my mum was bed-ridden and everything. It was nearly every night that. Jean (66) I*

It was clear that these experiences influenced Jean's attitude towards men. Her descriptions of these incidents were in answer to a question about relationships with men, suggesting that they had influenced the way in which she viewed these. Jean had suggested that she would 'chase a lad' if one tried to approach her, other than in friendship. However, interestingly, she did *not* relate these incidents and their effects to men in general: they did not deter her from socialising with men.

All the women who experienced physical/sexual abuse reported that this led to long-term consequences in relation to how they subsequently viewed men and sexual relationships. Katherine said that she would be more careful in future with regards to relationships, and Michelle had nightmares, flashbacks and worries about going out alone. Many years after being raped, this was the first thing that Jeanette spoke about when I interviewed her – she did not even wait for a question, and kept returning to the subject despite me asking her about other things. Jeanette continued to feel uneasy around men, and stated in the following exchange:

*Elizabeth: Do you feel okay dealing with men?*  
*Jeanette: No I don't, I don't feel okay about it, I like to be on my own.*  
Jeanette (50s) I

Like Susan, Jeanette clearly felt that being single was 'safer'.

Other respondents appeared to see danger in relation to sex, relationships and having children, without necessarily having experienced anything directly that might make them feel that way. It appeared that they had 'absorbed' what they saw around

them to the point where danger was ‘everywhere’. Sally, who referred to sexual safety throughout her interview (always unprompted), seemed to have developed an awareness of *multiple* dangers across a *number* of sources: including her own experience, her sister’s and mother’s experience, her friends’ experience, as well as from the media.

*On the news a nanny killed a child, and if I was (a mother, and was) out, I wouldn’t want that to happen. So I am quite happy with me and me alone [without a child]. Sally (25) I*

*If I got into trouble with a lad and I ended up in casualty...*<sup>167</sup> Sally (25) I

*I had a lot of bullying in my old house*<sup>168</sup>, *and the reason I haven’t wanted kids is because they might get ill*<sup>169</sup>. *And the reason I don’t want them is because I would be afraid that they would have the illnesses I had.* Sally (25) I

Here Sally suggests that nannies are linked with danger, that it is easier to be ‘alone’ than be a mother, that having relationships might lead to her being in hospital (her sister had experienced abuse from a boyfriend), and that a child of hers would be at risk from bullying, and (hereditary?) illness (the latter of these highlighted by Tymchuk and Andron, 1994, as a persistent assumption in relation to the parenting of people with learning disabilities). In addition to these comments, Sally mentioned AIDS more than once in response to questions that were unrelated to it, as well as the risk of emotional hurt when becoming involved in a relationship. Sally’s objections to having relationships, sex, and children were varied and, it could be argued, comprehensive. They cut across the physical and the emotional, and seemed to create a barrier to experiencing any kind of a sexual life. In relation to those women in this study who appeared to have multiple fears (particularly Susan and Sally), this echoes the findings within McCarthy’s (1999) research, where two of her seventeen respondents said that ‘everything’ about sex was ‘scary’, and only three had said that they had never been scared of sex.

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<sup>167</sup> Her sister was physically assaulted by a boyfriend, which might have influenced this remark.

<sup>168</sup> Sally appeared to be talking about when she was at school.

<sup>169</sup> Sally had previously told me that she had suffered two illnesses as a child that had left her physically impaired.

It was striking that female *Sex, Love and Relationships* course participants referred to health in particular when asked the question ‘what is sex?’ (See Appendix Twelve). Contraception was something that featured heavily in their discussion of this question. Although male participants mentioned contraception, it was not as predominant in their list of answers and they did not explicitly link it to pregnancy. As discussed in Chapter One, women with learning disabilities have historically had their sexuality regulated, including via sterilisation and contraception. McCarthy’s (1998a, 1999) research showed that women with learning disabilities today continue to experience this. This might help explain the emphasis on contraception by course participants. However, women more generally ‘carry’ the responsibility of sexual reproduction, and are also subject to regulation around safety in relation to pregnancy.

Although many women referred to fears in relation to sexuality, Katherine highlighted the positive effects of the *Sex, Love and Relationships* course on her overall opinion of men:

*I don’t see men as a threat now. I used to, a little bit. I’d only had bad experiences with men...I’m not as frightened as I was.* Katherine (54) **I**

I would further suggest that the *Sex, Love and Relationships* course had the potential to challenge some of the women’s fears surrounding sexuality. Nevertheless, it appeared that the *Sex, Love and Relationships* course might not have alleviated such fears to any great extent (Susan, Jean and Jeanette for example, had all been on the course, although Sally had not).

## **Sex, Relationships and Romance**

One of the normative discourses popularly associated with women generally is the ‘romantic discourse’ (Giddens 1992, Jackson 1993, Jackson 1999, Scior 2003). Carabine (1996a) has gone so far as to suggest that ‘love’ has taken over the importance attached to reproduction and motherhood as a normative gendered discourse. Scior (2003:786) describes romance in terms of: ‘boy meets girl, they get married and live happily ever after.’ Whilst this concept is similar to the conservative accounts described, where

relationships are seen in terms of marriage and parenthood, 'love', in the romantic discourse, is integral to this process. In this study, Katherine and Jane were unusual in that they both linked sex and relationships with love, where others did not. Katherine, for example, said the following:

*(Sex) is the most loving, most fulfilling thing you can do for your partner. It's the way to show that you love them. The way to show them you deeply love them, you know. Katherine (54) I*

Here Katherine makes direct, strong links between sex and love: sex is a way of communicating love, and (selflessly but in a way that is also mentally fulfilling) doing things for someone else (Mason 1996). Giddens (1992) has suggested that the way in which women relate to sexuality in terms of love and romance might herald a positive and liberating 'transformation' of sexuality. Jackson (1999) too suggests that love can form the basis of a resistance against a masculine definition of sexuality. However, Jackson has also highlighted feminist critiques of love that highlight the way in which this becomes implicated in the emotional and domestic labour that they enact within heterosexual relationships .

Katherine's linking of love and sex, which is also linked to her religious beliefs, brought her pain, as suggested in the following quote:

*I believe that if you're going to get married you should really and truly love and honour that person. And that's what I thought my ideal marriage would be. I thought it would be idyllic. Because at the time he was Christian. We married in a Christian setting. We'd done everything right, by the book. And yet, they say you don't know a person 'til you live with them. I wish, looking back, I wish now I had lived with him, you know, we had lived together. As companions. As like, lodgers, you know what I mean? Like shared a house with separate rooms. So I would have gotten to know what a man's tastes are, what a man's like. In that way I wished we'd lived together, if you get my meaning. Before marriage. It would have been like, companions. Katherine (54) I*

Katherine's outlook before marriage was typically romantic – she believed in 'true' love. Wedded with her religious beliefs (that seemed to elevate her views of sex and sexual relationships to a spiritual plane), and her trust in her husband's own religious convictions, this outlook influenced her belief that this marriage would be an 'ideal' one.

Unfortunately this was not the case. As already suggested, Katherine linked her 'naivety' with the way she had been brought up, and in relation to her impairment/learning disability. As seen in the quote, Katherine realised that getting to know someone (experience of the person, or experience of men – Katherine in particular referred to the differences between men and women, and of having little experience of men) might form a better basis for making a decision in relation to marriage.

Whilst I would suggest that Katherine's life reflected a more 'normal' life than other respondents (she had been married, had children, lived alone and had minimal professional assistance), and therefore was perhaps also more likely to reflect 'normal' (and gendered) discourses of sexuality, Jane too reflected a strong romantic discourse as seen in the following examples:

*Elizabeth: Right, you met him [Jane's boyfriend] at work?*  
*Jane: Yes, because I fell in love with him.*  
*Elizabeth: Why did you fall in love with him?*  
*Jane: Because I fancied him.*  
*Elizabeth: What made you fancy him?*  
*Jane: Being romantic.*  
*Elizabeth: He's romantic?*  
*Jane: Yes.*  
*Elizabeth: And you like that?*  
*Jane: Yes.*  
*Elizabeth: What kinds of things does he do that make you like him?*  
*Jane: Grown-up kisses [makes kissing motion with lips and head], like that.*  
*Elizabeth: Do you like that?*  
*Jane: Yes he does.*  
*Elizabeth: He does, but do you?*  
*Jane: Yes, I do, yes.*  
 Jane (39) I

*We like...being romantic and being Valentine's lovers. Jane (39) I*

Jane had had one boyfriend (the one she described here), but at thirty-nine lived with her parents, and was more dependent on professional services than Katherine. She also had little opportunity to spend time with her boyfriend, only spending time with him at their day service work placement. Nevertheless, for some reason which was not evident from her interview, she held strongly romantic views about her relationship that were not

particularly evident in other women's narratives, other than Katherine's. I would suggest perhaps that here is an example of the way in which dominant discourses relating to gender and romance were 'available' to Jane, despite her life experiences. Such discourses may have been drawn from the media, since she told me that she spent a great deal of her time at home in her bedroom watching television.

Unlike most of the women, Jane did not appear to hold contradictory or negative views of sexuality, and was consistently positive about her relationship with her boyfriend. Nevertheless, as suggested in Chapter Five, whilst she suggested that she wanted 'to be with him and be getting a relationship with him', and suggested that 'I'd like to be happily married', it was clear that the relationship was limited to a specific place (the day service work placement). Here, mainstream notions of romance are in tension with the restrictions Jane experienced. Although Jane wanted a romantic sexual relationship, this relationship was lived within narrow, regulated, boundaries. Although Jane described what might have been a private sexual encounter (related earlier in the chapter, where Jane describes what she and her boyfriend do in private), it is unclear when or where this might have occurred. Thus, the mainstream, and potentially regulatory romance discourse apparently available to Jane in theory, appears difficult for her to translate into practice.

Despite the 'lack' of a romance narrative within other respondents' accounts, Michelle alluded to the notion of 'Mr Right':

*I want to wait until the right person (to have children), if the right person comes along and everything... Michelle (29) I*

This idea that very specific individuals are 'meant' for each other, is again relatively gendered. Women are often constituted as desiring monogamous relationships, and as believing in 'the one' man who will be 'right' for her (Hollway 1984). This example also reflects the idea that one should wait until the 'right time' and the 'right' person comes along before having children, and that it would somehow be a mistake to have a child with the 'wrong' man. This echoes the religious overtones in Katherine's accounts of sexuality, in that it suggests a 'soul mate' exists for everyone. Like 'love' and 'romance', this notion of 'Mr Right' reflects mainstream regulatory discourses that focus

on ‘the one’ ‘true’ partner, rather than many. However, whilst these related discourses were referred to, relationships were associated more frequently with the notion of companionship.

### **Relationships and Companionship**

When Katherine reassessed her relationship with her husband, as described in the previous section, she suggested that whilst she had initially viewed her marriage in terms of love, and in terms of wanting the relationship to be ‘idyllic’, she now felt that she and her husband should at least have become ‘companions’ prior to the marriage, so that she could have found out ‘who’ he was. As suggested, most respondents tended to associate positive relationships (both ones they had experienced, and ones they desired) with the companionship they brought. Having similar interests, or being similar kinds of people, were considered important within relationships. This is seen in Vicky and Mary’s statements below:

*Elizabeth: What did you like about having a boyfriend, what are the good things?*

*Vicky: Talking.*

Vicky (28) I

*Elizabeth: What made you decide to get married?*

*Mary: Oh, I was lonely, and I wanted somebody to talk to.*

*Elizabeth: Did you fancy him, did you find him attractive?*

*Mary: Oh, oh no.*

Mary (78) I

These comments are perhaps not surprising, given the lack of opportunities available for this group to establish relationships and friendships, as discussed in Chapter Five. Additionally, these are ‘safer’ aspects of relationships, given the way in which many respondents associated sexuality with danger and risk, and friendships with safety.

In relation to the idea that relationships should be based on similarity between partners, Deborah and Sally described the following:

*Elizabeth: You say that you don't want a boyfriend, but thinking about if you did, what kind of person would he be like?*

*Sally: Someone like me! Who was into horror movies and art and creative writing. So, that person would probably be similar to me.*  
Sally (25) I

*Elizabeth: What would you have liked about having somebody else in your life?*

*Deborah: I would have liked him to take me around the bar and that. I would have probably took him to a café and got him a cup of tea, because I'm like that.*

Deborah (46) I

Like many (non-disabled) people, it was clear that Sally and Deborah looked for people like themselves to be with (or might have looked for – Sally for example was talking hypothetically as she said that she did not want a relationship). As suggested, these references in relation to companionship or similarity are more striking than references to love, romance, or desire, which were almost completely absent. Even in the following example, where Anne suggests that she might have been attracted to a particular man, being 'smart, decent and good-mannered' was more important than being sexually attractive:

*Elizabeth: Could I ask if you've ever found a man attractive before?*

*Anne: Well I have, yes.*

*Elizabeth: What did you like about that person? What made him attractive?*

*Anne: Smart, decent and good-mannered.*

Anne (55) I<sup>2</sup>

In some interviews there was a sense that respondents were sometimes unclear about what constituted a boyfriend as opposed to a friend, or that there might be a blurring between the two positions. Anne, for example, could not distinguish what might be different between her boyfriend and a friend, and in her second interview described



someone she had previously described as a boyfriend, as ‘really’ a friend<sup>170</sup>. Dorothy was at pains to make it clear that a close male friend was just that, a friend, and I sensed that this was on the basis that if she had not provided clarification, I might have made assumptions about her relationship with him that were not true – that having a male friend might be unusual or necessarily sexual. Four interviewees made it clear that they only wanted relationships with men as friends, as illustrated in the following comments:

*I like friends not boyfriends...I just don't want a boyfriend.* Dorothy (60) I

*I'm basically not interested in love. I am more interested in making new friends than I am having a relationship and settling down with anyone.* Sally (25) I

This emphasis on men as friends, not boyfriends, suggests that for these women there was a difference (despite Anne's blurring of her description of her friend/boyfriend) between a friend and a boyfriend. Sally marks this distinction between the two in terms of ‘love’, and ‘settling down’, the latter comment also suggesting that a relationship brings commitment and longevity – echoing Katherine's links between marriage (not necessarily relationships) and longevity. Dorothy linked having a boyfriend with kissing, which she did not like, and this was one of the reasons she gave for her not wanting a relationship with a man: ‘I've never had a boyfriend...I don't want one...because there'd be kissing and I don't like that.’ This kind of sexual activity might also be the reason why some of the other women said they chose to keep men at ‘arm's length’.

Anne described her friend/boyfriend in the following way:

*Elizabeth: What was it that you liked about being with him?*

*Anne: Well, he was friendly, and harmless, he didn't do anything wrong.*

Anne (55) I

Although it was not clear whether Anne was relating her friend/boyfriend's harmlessness with his friendliness (because he was friendly – or a friend – he was therefore harmless), his harmlessness was a reason for liking him. The fact that he did

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<sup>170</sup> It is possible that Anne described the man as a boyfriend to appear more sexually experienced, in relation to the topic under discussion, than she really was.

not do anything wrong (perhaps suggesting that other people had), is also important. These comments seem to reflect her low expectations in relation to friendships and relationships: it was *enough* for her friend/boyfriend to be ‘harmless’ and not doing ‘anything wrong’. Further, the way in which these women more generally relate relationships with companionship, suggests that such kinds of relationships might help to keep sexuality (and sexual love, romance, and desire), ‘distanced’.

## Femininity

I have already discussed romance in relation to women. Romance might be considered to be a key discourse in relation to the feminine role. In this section I will focus on some of the ways in which respondents related to further normative ‘feminine’ activities.

Four interviewees in this study described their pride in taking part in household tasks alongside other ‘everyday’ activities. Jeanette, for instance, illustrates this in the following example:

*(I) do food shopping...washing and ironing, cleaning, Hoovering, cleaning my room. I like doing all my washing, my ironing. I'm more independent. I go on my own to get weighed...(I) like doing my own cooking, own washing, own shopping. Look after your own money. Look after your own tablets. Look after your chequebook. Jeanette (50s) I<sup>2</sup>*

Whilst things like shopping, ironing and cleaning have been seen as stereotypically gendered tasks that women undertake (VanEvery 1996, Jackson 1997, Jackson 2007), I would like to argue here that these were not necessarily taken on by respondents *as* gendered tasks but as tasks they had previously been unable to perform and enjoyed doing. Jeanette, as described in Chapter Five, had lived in a long-stay institution for most of her life, and related these gender-related activities to the independence that she had outside of that institution: these activities are, for her, a ‘badge’ of independence. As discussed earlier, relating such tasks to independence underlines the still limited ways in which some respondents lived. Nevertheless, for Jeanette, these supposedly gendered tasks, that for other women might represent constraint, represent freedom and control.

Brown and Smith (1992) suggest that group homes (usually underscored by the principles of normalisation) are frequently based upon the nuclear family 'norm'. Thus women living in group homes often find themselves in a 'housekeeping' role; 'in this case servicing men whom they have not chosen and with whom they have no close personal ties' (1992:159-160). Scior (2003), who appears to be in agreement with this premise, argues that when the women in her study talked about doing household tasks, this practice was *necessarily* gendered. However, although some of the interviewees living in group homes in *this* study said that they did housework, and although housework is indeed gendered, there is no evidence in the data to suggest that these women did housework *because* they were women. The way in which women in this study took part in household tasks represents a more complex picture than the suggestion that they took part in them because they were women, and had somehow been disciplined into doing them and taking on this gendered role. However, it would be interesting to know whether such activities would be perceived by men with learning disabilities as examples of their 'independence', particularly since Forrester-Jones *et al.*'s (2002) research showed that some respondents (whether these were male or female was not made clear) disliked participating in household tasks.

Another association frequently made with women, with particular reference to femininity, is that they are concerned with clothes, hair and make-up, and the need to look attractive to others, particularly men (Hollway 1984, Bartky 1988). As Jackson (1996b) has pointed out, 'The desire to be sexually attractive appears to be profoundly important to women's sense of self-worth and closely bound up with the gendered disciplinary practices through which docile, feminine bodies are produced.' However, despite the way in which this desire for attractiveness and femininity might underscore the norms that potentially constrain women, Skeggs (2001) suggests that femininity (as expressed via clothes, make-up and hair products) is one of the few forms of cultural capital available to working class women, suggesting that this form of cultural capital might be a favourable asset for other marginalised and relatively powerless women.

Only two respondents seemed to be concerned with clothes, hair or make-up in relation to a stereotypical femininity or sexuality. Jane and Katherine, who also, perhaps

not coincidentally, associated themselves with a romantic discourse, associated themselves with more stereotypical and feminine modes of appearance. For example:

*Elizabeth:*     *What about [using] make-up and [doing your] hair? Do you like to do that?*

*Jane:*           *Ah hum. I like my hair done and make-up on and that.*

Jane (38) I

*Elizabeth:*     *What do you like about that kind of thing [activities on the course we are discussing]?*

*Jane:*           *How to be a model and that.*

Jane (39) I

Jane (like Katherine) described activities on courses at the organisation where the women's group met such as 'being a woman' – sessions run by the centre they attended – which focused on wearing make-up and getting 'dressed up'.

As Richardson (2007) argues, the relationship between gender and sexuality is mediated by discourses relating to other social factors such as race, class and age, and, it could be argued, disability. As suggested in Chapter Two, learning disability might form a 'master category' that overshadows gender (Davies and Jenkins 1997, Baron *et al.* 1999). Hence, women with learning disabilities, who have often been constituted as asexual, are also constituted as in some ways genderless and unfeminine (Clements *et al.* 1995, Scior 2003). Scior (2003) suggests that those who aligned themselves with gendered discourses in her own research compounded their negative experiences by doing so (both generally and in relation to learning disability). I would argue that such discourses, and the practices associated with them, might, nevertheless, have been perceived positively by those who adopted them, despite their stereotypical and potentially constraining nature. Scior suggests that the adoption of feminine roles by her respondents might be because of the 'need to see themselves and be seen by others as women' (2003:784). However, this articulation of 'need' casts this group as victims, and robs her respondents (and other women) of a sense that this might also be a form of agency (or as Skeggs describes, a form of cultural capital). As Barron (1997) suggests in relation to the disabled women involved in her research, the women's desire to take on feminine roles in some ways counteracted the passivity that they felt was associated with

their impairment or disability label. Thus, the adoption of household tasks and feminine roles might represent both a sense of agency and independence, as well as the desire to be seen as women (the latter being more directly associated with Jane and Katherine, who were more concerned with a stereotypically feminine appearance).

Although two of the interviewees in this study clearly identified with what might be considered to be feminine roles, most, however, did not. In terms of appearance for example, most spoke in terms of looking smart or clean. Julia drew my attention to a new top, which she described as 'smart'. Sally and Jeanette represented further examples of how stereotypically feminine activities were explained in practical rather than feminine terms:

*Sally: See, like my hair colour. That is my proper hair colour, there [pointing at a photo of herself on the wall].*

*Elizabeth: Your hair colour is more striking now. Why do you like to do your hair or nails?*

*Sally: Well, basically I don't like wasting money. And my sister is a hairdresser and (she has) bottles and bottles of dye for hair, and seeing as I don't want to waste anything...This colour (she's got) doesn't suit anyone else. So no one else wants it. So, I don't like having my hair dyed but seeing as I don't like leaving things I will use the bottle up before I grow my hair back to normal!*

**Sally (25) I**

*Elizabeth: Could I ask whether you ever feel sexy as a person?*

*Jeanette: No, not really.*

*Elizabeth: For example clothes –*

*Jeanette: I like wearing skirts or pants or make-up or hair done, hair cut and all that. And doing my nails and cutting my toe nails. I like getting my legs shaved and my arms shaved.*

*Elizabeth: Why do you like that?*

*Jeanette: 'Cause I like getting clean. I like a shower every morning. Clean and tidy.*

**Jeanette (50s) I**

These examples suggest that being clean, smart and practical were more important than being seen to be attractive, although it might mean that this was what 'attractive' meant to these women. It might also be argued that this constitutes Sally in particular, as someone who is not going to waste her time on looks. Making a point of describing her

love of ‘gore’ and horror over romance, Sally constituted herself as deliberately *not* stereotypically feminine. In relation to why she dyed her hair: it was practical, and she did not want to waste money. Arguably, this distancing from the feminine is also a distancing from the sexual. Sally for example chose clothes with pictures of animals on because she ‘loved animals’. This choice might also reinforce her identity as non-sexual, or as not ready to be an adult (animal motifs more usually being worn by children).

It was clear that the majority of these women did not constitute themselves in ways that might be described as stereotypically feminine. This suggests that normative discourses in relation to these femininities were either not ‘available’ to them, they had not been ‘picked up’, or perhaps they had even challenged them: respondents refused to ‘take on’ these normative accounts and related practices of gender and sexuality. For those that did adopt them, it is possible that these norms brought a sense of recognisable ‘womanhood’, given that access to this status might have been difficult. In the final section of this chapter, I will focus on the way in which respondents related to the label of ‘learning disability’, and the notion of ‘difference’.

## **Learning Disability and Sexuality**

Learning disability and sexuality have been historically associated in particular ways that have regulated the sexual lives of women with learning disabilities. If, as Foucault (1991) and Butler (1990, 1993, 1997) argue, we are constituted within discourses that we are effectively unable to think outside of, respondents, who were labelled as ‘different’, were also more likely to have seen *themselves* as ‘different’. However, this relies on a knowledge that they *are* ‘different’, that they have been labelled, and a knowledge of the associations made with that label. Whilst people with learning disabilities have been labelled, they are also sometimes ‘protected’ from that label by others, and might not always be aware that the label ‘learning disability’ has been ascribed to them (Davies and Jenkins 1997, Todd and Shearn 1997, Finlay and Lyons 1998). Nevertheless, the specific institutional experiences of women within this study, for example living in homes, and accessing daytime activities for people with learning disabilities, might give them a sense of the difference between themselves, and other

people. Additionally, as shown in Chapter Four, respondents were in some ways cast as 'other' through the accounts of family and staff. Here I will explore the ways in which interviewees in particular related to the label of 'learning disability' and the assumptions they associate with it, as well as the notion of 'difference', and the way in which these might impact on respondents' view of themselves in relation to sexuality.

Generally, interviewees' associations with the label of 'learning disability' were mixed: eight clearly associated with it, one did not, and a further four were unclear or held contradictory opinions in relation to it (the other three were not asked). In their interviews with twenty-eight men and women with learning disabilities using two residential services in the UK, Finlay and Lyons (1998) similarly found that respondents' associations with the label 'learning disability' were mixed. In this study, Katherine, for example, shifted between 'them' and 'I' in relation to 'learning disability', as seen in the following two statements:

*Sometimes they condemn them for having relationships. I know there have been a lot of people with Down's Syndrome, their parents have taken them to be sterilised, and I think that's awful. It's an awful shame.*

Katherine (54) **I**

*When I was on my own first of all, with the children, the health visitor came a lot, and I thought they were sort of judging me because they perceived that I wasn't quite able to mother the children, do you know what I mean? They perceived that with me having learning difficulties that I wouldn't be able to respond to their needs.*

Katherine (54) **I<sup>2</sup>**

This delay in identification, her 'othering' of disabled people, and her own vacillation between 'I' and 'they', suggests that disability and learning disability are not 'easy' identities. As suggested earlier, learning disability is seen to be a stigmatising identity and it has been argued that those so-labelled might 'distance' themselves from it (Harris 1995, Todd and Shearn 1997, Finlay and Lyons 1998, Rapley *et al.* 1998, Craig *et al.* 2002, Jahoda and Markova 2004). However, it is also important to note that this identity might not be seen as central to this group's lives (Finlay and Lyons 1998).

One woman who did not associate with the label 'learning disability' *also* attended services specifically for that group, not necessarily associating her use of a

service for people who have learning disabilities with herself. Mary said that she did not have a learning disability but met her husband in a day service *for* people with learning disabilities. Craig *et al.*'s (2002) research found that respondents gave reasons other than their 'learning disability' label to explain their presence in such services. Other interviewees in this study, as suggested, had mixed views in relation to their association with the label. There is a sense of 'distancing' in some of these women's accounts, as seen in Michelle's comment, where she shows that she is aware of the label other people have given her, but that she does not necessarily apply it to herself:

*I don't see myself as disabled. I just got told by other people.* Michelle (29) I

More specifically in relation to sexuality, Jean talked about the right of people with learning disabilities to a sexual life, and worked with the organisation where the women's group met to facilitate the *Sex, Love and Relationships* course. However, she also held ambivalent views on this, as evidenced in the following quote:

*Jean:*                *There was two people disabled [that she knew]. Boyfriend and girlfriend. Now they got married...but I don't think they would have a life of their own. A proper life of their own.*

*Elizabeth:*       *Why do you think they wouldn't –*

*Jean:*               *I don't know. It might be their learning disability they've got.*

Jean (66) I

Why Jean held what might be contradictory opinions is unclear. Although she felt that people with learning disabilities had the right to have relationships, she nevertheless found it difficult to understand how that might happen. I would suggest that this might be the effect of the multiplicity of discourses she had experienced, which included discourses suggesting a disabled sexuality was 'unintelligible', as well as the rights discourses reflected in the work of the organisation where the women's group met.

Learning disability is associated with notions of capability, and this is central to its definition (Department of Health 2001a), as discussed in Chapter Two. Such medical definitions of learning disability define it primarily in terms of individual 'lack', where people with learning disabilities do not fit the norm. This is reflected by the way in



which two interviewees referred to learning disability in terms of it being a ‘problem’<sup>171</sup>, as evidenced in the following examples.

*Elizabeth: Do you consider yourself as having a learning disability? Or as being disabled?*  
*Vicky: Problems.*  
*Elizabeth: You have problems?*  
*Vicky: Yeah.*  
Vicky (28) I

*They see my problem, what’s wrong with me. Sally (25) I*

This use of the term ‘problem’ underlines the relationship between impairment and the label learning disability, and these being a ‘problem’, as well as reflecting the medical or individual model of disability which also sees it as ‘problem’, and as an individual issue.

References to ‘being normal’ were also made. In the following examples Sally described non-disabled people as ‘normal’, and Jean saw herself as outside of the ‘disabled’ category because she had a ‘proper’ life and was able to do things without help. Susan on the other hand saw a relationship that she had had (with a man with learning disabilities) as ‘not proper’. If she had a relationship with one of the (non-disabled) sailors that she enjoyed flirting with and was attracted to, this would be a ‘proper’ relationship:

*Sally: Even I have normal friends. And if it were, like, to develop into a relationship and so on, plenty of people that I know have had relationships with normal people.*  
*Elizabeth: By normal, you mean non-disabled –*  
*Sally: Non-disabled, yeah.*  
Sally (25) I

*Jean: I’ve got a proper life. But I don’t think a disabled person would have a proper life like I have. They would like have to have somebody to take them out where I haven’t.*  
*Elizabeth: So a ‘proper life’ is being able to do things without help?*  
*Jean: Yeah, yeah.*  
Jean (66) I

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<sup>171</sup> None of the respondents associated with the label of learning disability as if it were a positive term.

*Susan: I would like a proper boyfriend.*  
*Elizabeth: Could you tell me what a proper boyfriend would be like?*  
*Susan: I would like one of those sailors. I would like one of them, a proper one.*  
 Susan (56) **I**  
  
*Elizabeth: Did you consider [your ex-fiancé] to be a proper boyfriend?*  
*Susan: Nah! I'd like a proper one.*  
 Susan (56) **I**<sup>2</sup>

Deborah, similarly, referred to her sisters, who had had 'real' boyfriends. Deborah saw her sisters as 'different' to herself in this regard, and related this difference to her (physical) impairment, stating 'but my sister and her boyfriend walked together, but we (she and her boyfriend) could not walk.'

Although none of these women described what they meant by 'normal' or 'proper' (with the exception of Sally, who responded to my prompt that this might be related to being 'non-disabled'), these words tended to be used in relation to people other than themselves, or in relation to circumstances that fell outside of their experience. Martin (2006), a man labelled as having a 'learning disability', has referred to the notion of a 'real life', something that exists outside of his experiences and is denied to him by society. Similarly, disabled respondents in Barron's (1997) work, and men with learning disabilities in Wheeler's (2007) research, referred to the boundary between themselves and others in relation to 'normality'. Thus, the notion of 'proper', I would suggest, is similar to 'real life' and 'normality', and that these are things that respondents feel they do not have.

Katherine was one of only three interviewees who talked about how others might see her, as a woman with a learning disability. In the following example she described how this impacted on her:

*I had the feeling that they didn't trust me with the children, but I sort of like proved them wrong, you know. I brought them up on my own and they both turned out to be sound, and there's the youngest one with children of his own now, so I must have done a good job [laughs].* Katherine (54) **I**<sup>2</sup>

*It can be quite difficult because people look down on you if you have a learning disability. They think that you're not up to it, you're not able to function as a*

*woman, you know. You haven't got the same feelings, you know. And you're more vulnerable as well.* Katherine (54) **FG**

Katherine talked at length about her feelings in relation to not being trusted as a mother of two children. She felt proud that she had 'proved people wrong' in bringing up her children successfully. Katherine also highlighted the way in which others felt that women with learning disabilities might not have the same feelings as other women, showing her awareness of accounts that suggested that women with learning disabilities might not just be less capable of being mothers than non-disabled women, but also feel differently in relation to sex and/or relationships.

Over half of the interviewees related to learning disability, or their own difference to others, in terms of (in)capability. This was expressed by five women in relation to their own capabilities. One woman suggested that she did *not* have a learning disability because she could 'do things', and another suggested that *others* saw her as less capable than non-disabled people because of her learning disability. The remainder talked of others with learning disabilities being less capable than non-disabled people, or themselves as less capable in the sense that they and their peers (for example the people with learning disabilities they lived with) were 'different' to other people. Finlay and Lyons (1998) found that their respondents linked their lack of ability to learning disability, both in general terms – for example not being able to do 'anything', and specific terms – not being able to dress, or read and write. Interviewees in this study made similar claims.

Further, five linked their own lack of capability with not being able to cope with marriage and having children, though, interestingly, this concern was less strong in relation to sex or having relationships<sup>172</sup>. The following quotes relate to parenthood:

*The reason I'm not interested in kids is because I have trouble looking after myself, and if there was a kid and me, I wouldn't be able to cope.* Sally (25) **I**

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<sup>172</sup> This might be because marriage and parenthood were seen as more important. Parenthood for example was seen as something that might have been 'missed' (and wanted) in some women's lives, and marriage too but less so. Relationships (without marriage) seemed to be lower on the list of what might have been desired, with sex (as practices or acts) at the bottom.

*Jeanette: I don't have children. I've got my tubes tied from having children.*  
*Elizabeth: Is it something you might have liked though?*  
*Jeanette: Not really. I don't want a baby.*  
*Elizabeth: Right, is there any reason why you don't?*  
*Jeanette: Because I don't want to go through it.*  
*Elizabeth: Can you think what might make that a difficult thing for you?*  
*Jeanette: Aye, I can't look after it properly.*  
*Elizabeth: Do you think that?*  
*Jeanette: I think that.*  
*Elizabeth: Has anybody else told you that?*  
*Jeanette: My mum told us I can't look after myself. I can't look after one.*  
 Jeannette (early 50s) **I2**

Having children was referred to by respondents more frequently than relationships or marriage, as desirable. As suggested earlier, having children is central to many women's sense of self as women.

Thus, many respondents' accounts suggested that they were aware that they were 'different' to others. This is in contrast to Watson's (2002) findings from UK interviews, conducted with fourteen disabled men and fourteen disabled women (not people with learning disabilities). This research showed that respondents held a social model viewpoint where difference was only associated with the way in which non-disabled people viewed them. Whilst interviewees in *this* study tended towards seeing themselves as fundamentally, or essentially, 'different' (for example because they were less capable than others)<sup>173</sup>, some aspired to a 'normal' life and were active in the 'doing' of 'being ordinary' (Rapley *et al.* 1998:824). For example, Jean and Michelle highlighted their capabilities in relation to looking after children, contrary to what they had been told; underlining again the importance respondents seemed to attach to children:

*Mind I can look after babies, I used to look after my brother's babies.* Jean (66) **I**

*My dad says...I can't look after him [a baby, if she had one] he'll have to look after itself. If I had the right support with the baby...that's what me mum and dad's there for, support.* Michelle (28) **I**

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<sup>173</sup> Sally, however, whilst regularly referring to others as having a 'normal' life in comparison to herself and her friends with learning disabilities, abruptly qualified this viewpoint near the end of her interview, by asking 'What is normal, anyway?', echoing a similar question put by one of Watson's (2002) disabled interviewees, and reflecting, momentarily, a social model perspective.

Booth and Booth (1994) suggest that there is a 'deficiency' perspective taken in relation to the parenting skills of people with learning disability. This focuses on the ways in which people with learning disabilities are *not* capable of being good parents, rather than looking at the ways in which they *are* capable. As Booth and Booth's research shows (eighty-two interviews with sixteen men and fourteen women with learning disabilities), people with learning disabilities can become 'capable' parents.

## Conclusion

In this chapter I looked at the meanings respondents gave to sex and relationships, their views and practices in relation to femininity, and how they relate to 'learning disability' and 'difference'. The accounts that many respondents gave linked sex, marriage and parenthood in a 'natural' trajectory, suggesting that marriage is lifelong and monogamous, and necessary for parenthood. These accounts reflected discourses of sexuality as a 'biological need' and/or primarily as procreative. Same-sex relationships sat outside of this framework, and were difficult for some respondents to comprehend. I went on to examine the ways in which many respondents viewed sexuality negatively, although occasionally, positively; before showing how some respondents' accounts reflected discourses of sexuality that framed it as dirty, embarrassing and shameful. I then looked at respondents' accounts in relation to safety, and sexual safety, before looking at romance and companionship discourses as well as the way in which 'femininity' was reflected in respondents' accounts. I concluded by describing how many respondents saw themselves as 'different' to other people, and how this affected the way in which they viewed themselves in relation to sexuality.

The accounts and discourses reflected in this chapter show that learning disability appeared to impact on the way in which respondents viewed themselves in relation to sexuality. Nevertheless, mainstream discourses of gendered sexuality were also reflected in some respondents' accounts. Whilst these discourses are potentially constraining, they might also offer this group access to 'intelligible' gendered and (hetero)sexual identities.

## CHAPTER SEVEN

### Conclusion

This thesis has outlined research that aims to explore how a particular group of women who have learning disabilities give meaning to sexuality, and the ways in which family and formal institutional accounts and practices might be influential in this process. This has involved the analysis and interpretation of data drawn from fieldwork with people with learning disabilities, in particular, interviews with sixteen women, contextualised and supplemented by data resulting from a focus group with six women, and observation on a course for both men and women which had been accessed by over half of the interview and focus group participants. The study used a theoretical framework that took the social model of disability as a starting-point, as well as concepts developed by symbolic interactionists such as Gagnon and Simon (1974) and Plummer (1981, 1995), as well as Foucault (1973, 1989, 1990, 1991). This framework has served to underpin the argument that I make, that disability, sexuality and gender are socially constructed and regulated via social norms, albeit in different ways. In summary, this study has explored:

- where and how research respondents learnt about sexuality, teasing out some of the accounts and discourses around sexuality, learning disability and gender that respondents reported coming into contact with
- the kinds of family and service practices that impacted on the agency of respondents, and underlined or challenged the kinds of discourses of sexuality they reported encountering
- the various accounts and discourses of sexuality reflected in respondents' own opinions on sexuality, gender and learning disability

A number of consistent themes and issues have emerged from this exploration. These include the way in which respondents have been cast as, and cast themselves, as 'different', childlike and vulnerable, as well as dependent and lacking capability (particularly in relation to motherhood), and sexuality as 'unsafe'/'wrong'; the way in which respondents' lives were significantly constrained and characterised by a relative lack of choice; and how to some extent respondents' own narratives reflected those of significant others, as well as the lack of a sense of their own sexuality. The *Sex, Love and Relationships* course in some ways countered prohibitive accounts respondents encountered within other settings, but also appeared to uphold particular gendered accounts of 'difference'.

Many of these themes suggest that respondents' lives might be dominated by their 'learning disability' status. At the same time, normative 'mainstream' gendered and sexual accounts were evident within institutional accounts, as well as respondents' own. These included, what appeared to be, 'older' or more 'traditional' normative accounts that relate sexuality to marriage and having children (regardless of the women's age and generational differences), as well as accounts that whilst not widespread amongst respondents, were evident: accounts that linked sex with romance, and independence with gendered household activities. Such accounts, and the discourses they reflect, can act to constrain such women, particularly where they underline the passivity associated with being a woman, and being disabled (Oliver 1990, Morris 1993b). However, since some respondents associated stereotypically feminine activities with autonomy, whilst this group might indeed be disciplined into particular gendered roles, some of these roles could also give them access to an 'adult independence', and perhaps a sense of 'womanhood'.

The research findings confirm a number of themes present in previous empirical work with disabled people in relation to sexuality. For example:

- a relative lack of knowledge in relation to sexual matters (Brown 1983, Morris 1989, Heyman and Huckle 1995, Shakespeare *et al.* 1996, Gillegie-Sells *et al.* 1998, Lesseliers 1999, Johnson *et al.* 2002)

- respondents being cast as ‘eternal children’ (Craft 1983, Heyman and Huckle 1995, Shakespeare *et al.* 1996, Scior 2003) or vulnerable (Robbins 1990, Heyman and Huckle 1995, McConkey and Ryan 2001)
- respondents’ sexuality might still be perceived to be problematic, with parenthood particularly so (Christian *et al.* 2001, Cuskelly and Bryde 2004, Wheeler 2007)
- respondents appear to be subject to policing and control (Brown 1983, Robbins 1990, Heyman and Huckle 1995, Gillespie-Sells *et al.* 1998, Johnson *et al.* 2002, Scior 2003, Parkes 2006)
- there is a lack of emotional and physical space in which to have a sexual life (Lesseliers 1999, Löfgren-Mårtenson 2004, Abbott and Howarth 2005)

More specifically, findings confirm, in relation to the little research conducted about women, that this group tend not to feel sexual (McCarthy 1999), to perceive themselves as sexual agents (Lonsdale 1990, Lesseliers 1999, McCarthy 1999, Scior 2003), and do not have positive experiences of sexuality (Millard 1994, Lesseliers 1999, McCarthy 1999). Whilst these findings appear to support, at least in part, the effects of a ‘learning disability’ status, it also underlines the way in which women with learning disabilities are subject to gendered and sexual norms, a finding less evident in the wider empirical literature, perhaps because it has rarely been addressed (McCarthy 1999, Scior 2003, Abbott and Howarth 2005), although explored theoretically to some extent elsewhere (Brown and Smith 1992, Brown 1994, Williams and Nind 1999).

Despite this seemingly negative snapshot of life for these women, I think that it is also important to highlight that many also resisted the ways in which they had been constituted, and/or the practices that served to constrain them. For example, many of the women asserted their ability to look after children, and emphasised their independence more generally. Further, it is important to note that some women *had* reported positive experiences of sex, sexuality and relationships (Jane, for example, spoke in consistently positive terms about the relationship she had with her boyfriend), or had reported having



had more opportunities to experience these than others (Katherine and Charlotte, for example had children, and others had been, or were, married).

Here, I would like to focus on a number of issues raised within the data chapters, and explore their implications further. Whilst this study is necessarily limited in its generalisability, I would like to highlight particular ways in which its implications might be of interest to practitioners, as well as academics.

### **Experiences of Sex, Relationships, and Having Children**

Despite the fact that a number of respondents had experiences of sex, sexuality and relationships, these numbers were nevertheless low. In particular relation to the way in which respondents felt about both their own sexuality and sexuality more generally, there was what might be described as a ‘missing discourse of desire’ (Fine 1988). This suggests that respondents either did not want to have sex, feel sexual or have relationships (confirming their constituted ‘asexual’ status perhaps), or, taking the view that sexuality is constructed (Gagnon and Simon 1974, Plummer 1981, Foucault 1990), they have had little opportunity or encouragement to develop or explore these aspects of their lives. Data suggests that both of these possibilities might be the case.

As highlighted, generational differences did not appear to be a significant influence on this group’s thoughts on, or experiences of, sex. Given the changes in the way in which people with learning disabilities have been perceived, particularly over the last century, and even more so as expressed within policy, as well as wider social trends and changes in relation to sexuality occurring, notably since the 1960s (Haste 1994), one would expect to see differences between the kinds of sexual accounts that younger and older respondents came into contact with, and differences in their experiences. One would also assume that the younger group might feel differently about their own sense of sexuality or sexual identity.

Although to some extent younger respondents reflected what might be different or more progressive experiences (Sally and Vicky thought that their parents would have had no problems with them having relationships), these were tempered (Julia’s parents told her she could *not* have a relationship, and Vicky’s parents told her not to let a man

'touch' her). I would argue that despite their age and the increasingly rights-based context within which they live, these younger women still faced barriers to learning about, and experiencing sexuality. These experiences seem to be more in tune with those of their older learning-disabled peers, than those of their non-disabled peers of a similar age. Data, therefore, suggests that despite policy changes, residual attitudinal barriers may still in place, particularly in relation to Julia's comments about how she was not 'allowed' to have relationships, children, or to get married. Even where lack of training or policy has influenced staff hesitancy in supporting client sexuality, as indicated within wider research (Robbins 1990, Christian *et al.* 2001, McConkey and Ryan 2001), the apparent need for training or guidance is predicated on the notion that people with learning disabilities are 'different' where sexuality is concerned.

Whilst I am not suggesting in response to these findings that women with learning disabilities, or the respondents in particular, should want sex, feel sexual or have relationships (as Shakespeare, 2000a suggests: 'Perhaps we shouldn't forget to value celibacy, and friendship, and the other parts of life'), I do think that it is important to explore the social reasons why these women are not feeling sexual, or not having relationships, or not becoming mothers. The data and analysis here is necessarily limited in this exploration, however. Nevertheless, I would like to highlight a number of issues emerging from this research that are worthy of further consideration.

Findings suggest that the kinds of discourses on sexuality that respondents encountered tended to be either negative and/or normative. Whilst the *Sex, Love and Relationships* course represented a significant challenge to these, there were indications that respondents, nevertheless, held contradictory views on sexuality, and reflected contradictory discourses (for example, one respondent held the view that people with learning disabilities had sexual rights, but also found it difficult to understand *how* they could have a sexual life). Courses on sexuality for people with learning disabilities, as well as wider services, might need to be aware of the way in which they operate within a field of competing discourses of sexuality, with some discourses suggesting that people with learning disabilities are not sexual. This is already something that the *Sex, Love and Relationships* course does acknowledge, by challenging the way in which participants might be powerless or less-than-adult, and through role plays dealing specifically with

these issues. Such courses, and wider services, might also need to be aware of the gendered nature of sexuality, and how they address this. Therefore, it might not be enough to promote inclusion, choice, rights or independence as if the field in which these concepts operate is neutral, both in terms of the differential status of 'learning disability', as well as in relation to gender.

As suggested by the findings, institutional practices are influential. For example, data suggested that whilst respondents lived in an increasingly rights-based context, with more apparent choice and control, their choice was still considerably limited in practice. Importantly however, few appeared to recognise this limitation, presumably because the choice and control they currently had represented an *increase* in choice and control. Additionally, it might be explained by a lack of awareness of the choices that could be available to them, or perhaps a lack of awareness that these choices could apply to *them*. Further, this group are, due to the historical limitation on their choice, socialised into accepting this limitation and are therefore, arguably, ill-equipped to take up the rights they are offered. It is not enough, I would argue, to suggest that people with learning disabilities have rights: there is a need to be critical in relation to what those rights are and how they are to be met. There might also need to be further consideration in relation to how sex sits within the current concepts of rights – what do we mean by sexual rights within a neoliberal context, and is this form of sexual rights available to people (and more specifically women) with learning disabilities?

Findings also suggest that respondents were not accorded the emotional and physical space to pursue relationships. Privacy was an issue for a number of respondents and the need for staff to respect service users' private space might need to be given greater emphasis by service providers. All those respondents interviewed in their bedrooms had single beds (as did all the service users I worked with as a professional)<sup>174</sup>. This might indicate two things: firstly, service users' lack of adult status, and secondly, the assumption that they will be unlikely to share their bed with anyone else. Social opportunities and social space within which service users could develop and maintain relationships, and again, this 'lack', might need to be more fully considered, with particular thought given to the possibility that these might be *sexual*

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<sup>174</sup> These interviews occurred in service settings, so I can only comment on these.

relationships. Cambridge (1996b) has argued that whilst choices and rights have been central to service delivery, sexuality has tended to be considered outside of this framework. As suggested, opportunities for parenthood, as well as forming relationships, seem to be few. As the *Valuing People* White Paper highlights: 'Support for disabled parents, including those with learning disabilities, is patchy and underdeveloped' (Department of Health 2001a:81). Theoretically such considerations should be considered by services as a matter of course. Despite changes in the perception of people with learning disabilities in relation to sexuality and parenthood, as suggested by other research, service principles are not necessarily met in practice, and this is sometimes dependent on individual staff. As Craft and Brown (1994) highlight, if people with learning disabilities are to exercise more power, someone else (parent or carer) must relinquish it.

Of course, the focus of this study is not only on services, and the influence of parents on respondents has been shown. Therefore, I would suggest, that the parents of people who have a learning disability might benefit from more support, including courses to help them deal with, and support their adult children's sexuality. Heyman and Huckle (1995:153-4) have argued that 'Whilst other parents acknowledge their children's sexuality by default, parents of adults with learning difficulties who wish to enable them to develop sexual relationships may have to be actively involved [in supporting their children's sexuality]...Thus demands are placed on them which are not normal in our culture.' They further argue that parents' concerns need to be addressed alongside the rights of individuals with learning disabilities. Whilst this might challenge or highlight the boundaries between public (services) and private (families), the existence of such support might be crucial in ensuring that service principles supporting sexual rights, do not conflict with those of parents (Parkes 2006).

I would also like to highlight the issue of sexual abuse, in terms of sexual rights and autonomy, before moving on. As Keywood suggests, the sexual safety of people with learning disabilities cannot be assured unless their sexual autonomy is promoted by services (2003). Sexual rights include the right to sexual information that helps women with learning disabilities to avoid abusive situations. Whilst fears that women with learning disabilities are sexually vulnerable might explain why this group are shielded

from sexual information, this lack of information leaves them vulnerable to abuse. Craft and Brown (1994:12) argue that:

There is a path between over- and under-protection of service users. It will be a different path for different individuals, but the process of delineating it should be service principles of good practice rather than be left up to one member of staff.

Thus, services have a duty to work with the tension between protection, and the individual's right to live their lives as they wish. As discussed, data suggest that those women in this study who had been abused would have liked more opportunities to talk about this experience. The right to sexual information might also be extended to the right to access appropriate support.

## **Gender and Learning Disability**

Gender did not seem to play a dominant role in this group's perception of themselves. Although some women participated in activities that were traditionally gendered, this was not necessarily *because* they were gendered, as suggested. Conversely, Scior (2003) suggested that her respondents explicitly associated with stereotypical female roles. Both studies were small-scale and it would be difficult to infer anything from the differences in these findings. Further, two of the women in this study *did* refer to and enjoyed taking part in what might be considered to be stereotypical feminine activities: wearing make-up and dressing in feminine ways. Both of these women also held what might be considered to be stereotypically gendered romantic viewpoints. In these cases, I would concur with Scior's hypothesis that such identification might emerge out of the need by these women to be seen as 'women'. Women who have learning disabilities have been denied such feminine roles in the past, and in adopting such roles they might gain some kind of access to 'womanhood'<sup>175</sup>, even if these roles are devalued by others. As suggested earlier, one of the criticisms of advocating a 'normal' or 'ordinary' life for people who have learning disabilities, is that this also involves advocating 'ordinary' gendered roles (Brown 1994). However, whilst it might be wrong not to challenge the

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<sup>175</sup> And therefore (arguably) adulthood.

ways in which gender norms affect women, and might also affect women who have learning disabilities, it might also be useful to recognise that these roles have been previously denied to them, and that it might also be wrong to remove the possibility of having those choices.

Here I would also like to highlight the particular issue of motherhood. Historically women have been seen (whether rightly or wrongly) in terms of being carers, and more particularly mothers, and this is one of the ways in which they have been socially valued. As Hockey and James (2003) suggest, adult women live with the rhetoric that they have a biological clock which tells them to ‘hurry up’ and procreate. Women with learning disabilities have, on the other hand, been actively discouraged from doing this. Despite policy, and supposedly wider attitudinal changes, that suggest that this group should have the right to parenthood, only two respondents had children (one of whom described how she had been ‘policed’ when her children were born because of her learning disability status). Others described being told that they could not or should not have children. Some women also *felt* that parenthood was not a possibility. As Hockey and James (2003:149) state: ‘while employment represents an important transition to adulthood for young men, it is motherhood which contributes significantly to a mature feminine identity.’ Womanhood (and adulthood) is implicitly related to motherhood; a role that few had experienced.

Another important point I would like to highlight, is that whilst ‘being a woman’ was not necessarily seen as important by most respondents, they nevertheless saw masculinity as ‘other’. Many described negative experiences with men and linked men with danger. These were experiences with strangers, as well as men known to them, and included rape, physical attack and simply the threat (or thought) of such things; even sexual ‘joking’ was perceived as problematic and upsetting. Additionally, respondents who had experienced violence also felt some responsibility for this, and although this was explicitly linked by two of the respondents to their status as person with a learning disability, this feeling of responsibility is also gendered in that non-disabled women have felt similarly (Lees 1993). As I have suggested, women are often charged with taking responsibility for both their own, and men’s, sexuality.

Moving back to respondents' more general lack of association with gender, this might point to the development of a sense of self with reference to a 'master status' or 'master category' of learning disability (Davies and Jenkins 1997, Baron *et al.* 1999) *over* that of 'being a woman'. Being categorised as having a learning disability has effects that can potentially override the effects of all other categorisations. However, the adoption of the status of learning disability by respondents was also far from clear-cut in the data. Whilst some related to this label, others did not, and many adopted a contingent relationship with it: 'accepting' it, then denying it, and occasionally challenging it. As Scior (2003) argues, negative constructions of learning disability remain powerful despite current and more liberating references to 'choice', 'control' or 'social inclusion', which might explain the vacillations and difficulties in respondents' association with the label. Although a learning disability status appeared to be dominant, this status was therefore not an unmediated one, and as Brown (1994) and Scior (2003) have suggested, being perceived as a woman can work to compound the negative experiences of people with learning disabilities. In combination, they place women who have learning disabilities in a particularly difficult position within services that fail to be aware of the effects of gender differences, or who underline these through normalising practices.

The way in which those with learning disabilities have been cast as childlike has been of particular note within this thesis and elsewhere. Data suggest that some respondents felt themselves to be seen as less than adult. Baron *et al.* (1999:496) suggest that the transition for people with learning disabilities from youth to adulthood is 'extended (perhaps permanent), partial and with a stable and dominant identity (learning disability) continuous across the years.' Although, as Thomson (2004) argues, signifiers are changing (she suggests that, for example, economic consumption is occurring earlier but economic independence later), sexual activity is not only a continuing marker of adulthood, it has also become one of the most accessible for young people, in particular. Hockey and James (2003:57-8) too suggest that:

despite today's fluid process of classification and transition...the more rigid pattern of the modern western lifecourse which emerged in the mid-nineteenth century continues to occupy a hegemonic position...parenthood for example, is nonetheless still perceived as an important temporarily located marker or turning point in the biographical movement towards adult identity.

This finding is particularly important given the way in which women too are constituted as 'passive' (Giddens 1992), thus compounding this aspect of respondents' lives (Oliver 1990, Brown and Smith 1992, Morris 1993b).

### **Method: Impacts and Limitations**

I would like to highlight the ways in which this research is limited in terms of its generalisability, and some of the ways in which this research was 'difficult'.

This study deals very specifically with a relatively small group of women, who are white, and who I have identified as heterosexual<sup>176</sup>. The differential experiences relating to class have also been elided for the reasons described in Chapter Three. Research was also conducted with women who were relatively able to express their thoughts and feelings, and did not include anybody who might have been described as having a 'severe' or 'profound' disability. As Swain and Thirlaway (1996) have highlighted, there are particular issues around sexuality and this group, and that it might be overly idealistic to assume that those with severe and profound learning disabilities can have a sexual life. Additionally, although this study focuses on gender, an exploration of gender differences has been limited firstly, by the single focus on women in this research, and secondly, on the lack of comparable research on men beyond.

Additionally, comparison between respondents was difficult, due to their different levels of experience, and ability to report those experiences. Quantity and quality of data therefore differed greatly between interviews. For example, I had approximately four hours' worth of detailed and discursive data from one respondent, and twenty minutes of 'yes-and-no' answers from another. Further, whilst I had a common interview schedule, not all questions were asked with each interviewee, with some questions being left out of those interviews where respondents talked about 'difficult' experiences on the basis that they simply did not 'fit' or 'feel right'. This research can only therefore be a 'snapshot' in time, and of a particular, and limited group of women, where comparisons between them can only be tentatively made.

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<sup>176</sup> See discussion in Chapter Three.



Another limitation is due to the relationship between the construction of meaning and the role of the psyche – a realm that is both difficult to comprehend and theorise, and difficult to explain (both as research participant and as researcher in the role of interpreter). The role of the psyche has not been pursued in any detail within this thesis, mainly due to the strong focus on the socialisation process, and the location of this thesis within a sociological paradigm; the research aimed to highlight the importance of *others* in the development of respondents' sexual understandings, and sense of sexual self. However, as Marks (1999) suggests, an exploration of the psyche *does* have a place within disability research, and this aspect of social construction is acknowledged.

Given the entangled nature of gender, learning disability and sexuality, as well of the different sources of particular discourses, it was difficult to affirm definite links between what respondents were told about themselves and about sexuality, the practices that they experienced in relation to sexuality and autonomy, and how respondents *themselves* viewed sexuality. Thus, I leave the research with more questions than answers: Why were some women (apparently) comfortable discussing sexuality whereas others were not? Why did some women relate relationships to romance when others related it to companionship? What exactly has caused the 'silence' on sexuality in many of these women's lives?

### **Using Theoretical Frameworks: Difficulties and Deliberations**

The theoretical frameworks used in this thesis are perhaps a little disjointed: they do not necessarily fit seamlessly together. For example, whilst the social model of disability is most often not linked with the work of Foucault, both bodies of work describe how categories and identities are socially constructed, and link this social construction to the development of specific 'expert' knowledge(s). Such concepts have underpinned my understanding of the topic as a whole.

Such work (that of Foucault, Gagnon and Simon, Plummer and the social model of disability), and work based upon its concepts, models and theories, has also helped me to explore more *specific* aspects of the data. Such aspects included the role of gendered and sexual norms (work by Hollway, 1984; Giddens, 1992; Jackson, 1999;

Skeggs 1997, 2001 and Butler, 1999 has been useful in this regard) and the intersection of disability and gender (with work by Morris, 1993b; Brown and Smith, 1992; Brown, 1994; Barron, 1997; Williams and Nind, 1999; Kallianes and Rubenfeld, 2002 and Scior, 2003 useful here). Such work has thrown light on the way in which gender/sexuality/disability operate and helped me move beyond the assumption that learning disability might act as a master identity, to an understanding of identity as more complex, fluid and contextual. This work also shows how particular aspects of identity can be viewed as both positive and negative. For example, femininity might be seen to subordinate women but might also be seen to offer them a degree of power, albeit constrained. These frameworks have, necessarily, led me to rethink my own tendency towards seeking relatively straightforward understandings of respondents' lives. Associated with this acceptance of complexity, I have also had to move away from thinking in terms of structural inequalities (tempting when utilising the social model), power as something that is held rather than exercised, and of binaries: them/us, good/bad, choice/no choice, disabled/non-disabled and so on.

The work on norms in particular has led to some interesting questions that I am not sure can be answered, particularly within this thesis: Are the women inside or outside of the regulatory norms of (hetero)sexuality? (And here it is worth highlighting Butler's (1999) assertion that gender, for example, is an impossibility – it is a fantasy that none of us can achieve.) Whilst a learning disability 'master category' does seem to be at play, at least in the experiences respondents had in relation to family and services, this is challenged and contradicted by the way in which these women might also be being encouraged to attain 'normality' within such contexts, and through the 'traditional' norms associated with sex, marriage and having children they came into contact with. Would respondents become 'intelligible' sexed and gendered subjects if that normality was gained? Does learning disability itself mark the boundaries of intelligibility (along with other markers like particular sexual practices or identities), given its construction as 'other than normal'? How do the intersections of gender, learning disability and sexuality work together in relation to intelligibility? And if women with learning disabilities gained intelligibility as sexed and gendered, what would that mean?

It is worth noting here that several respondents may be described as having transgressed norms simply by having sex, getting married, and having children. As suggested, Brown (1994:141) has argued that those people with learning disabilities who have 'normal sex' are seen as 'breaking the rules'. Keywood (2003:30) has further asserted that service attempts to support the sexuality of people with learning disabilities has been less a 'manifestation of normalisation in action, but rather an act of rebellion from established social norms.' It is also interesting to ask whether those respondents who do not take on wider social roles and norms are defying and challenging them, or accepting that they are not intelligible within them.

### **Taking the Research Forward**

It is clear from the above discussion that there are several ways in which this research could be taken forward. Research in relation to gender and learning disability, sexuality and learning disability, and the way in which people give meaning to sexuality, particularly in relation to sexual and gendered norms, is thin on the ground, and research into any of these areas would be beneficial.

The research outlined in this thesis could be taken forward to include interviews with professionals and parents, people with learning disabilities from other or different ethnic backgrounds, men with learning disabilities (as I have already highlighted, comparable research with men is lacking), or people who identify as lesbian, gay, bisexual or queer. More attention could also be paid to class, trying to work through some of the difficulties I touched on in Chapter Three. Further, as Owens (2007) points out, some methods are more conducive to research with people with learning disabilities, particularly narrative research<sup>177</sup>, and more attention to the way in which data is gathered in any further research with people with learning disabilities would be valuable, particularly in light of some of the difficulties I experienced gaining material from less articulate respondents. Finally, taking a more participatory approach, involving respondents in the planning of research, might also be useful, and more emancipatory.

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<sup>177</sup> Although my own research refers to 'narrative', this does not relate to the more specific narrative research as method that Owens advocates.

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## APPENDICES

### Appendix One

#### Letter to women's group facilitator – negotiating initial access

[My address]

[Facilitator's address]

15<sup>th</sup> August 2003

Dear [...]

You may remember we communicated via email way back in April about the possibility of conducting my PhD research with the women's group at [...] and that the research depended on my getting funding. I have just been informed that I *will* be getting funding and the PhD will commence in October.

You suggested that a first step would be to meet the group at one of their monthly meetings. If this is still OK, then the October or even the November meeting would be best as I will have started the PhD and I will be able to take time off work then.

I attach the most recent copy of the research proposal – it has changed a little since we last communicated. However, it isn't set in stone, and can be changed relatively easily. I am also considering focusing on the subject of sexual identity as a more specific component of sexuality, but haven't discussed this with my supervisors yet.

Please let me know what you think; my email address and telephone number are above.

Best wishes and thanks for your time,

Elizabeth Brace

Appendix Two

**Examples of visuals used in presentation to women's group March 2004**

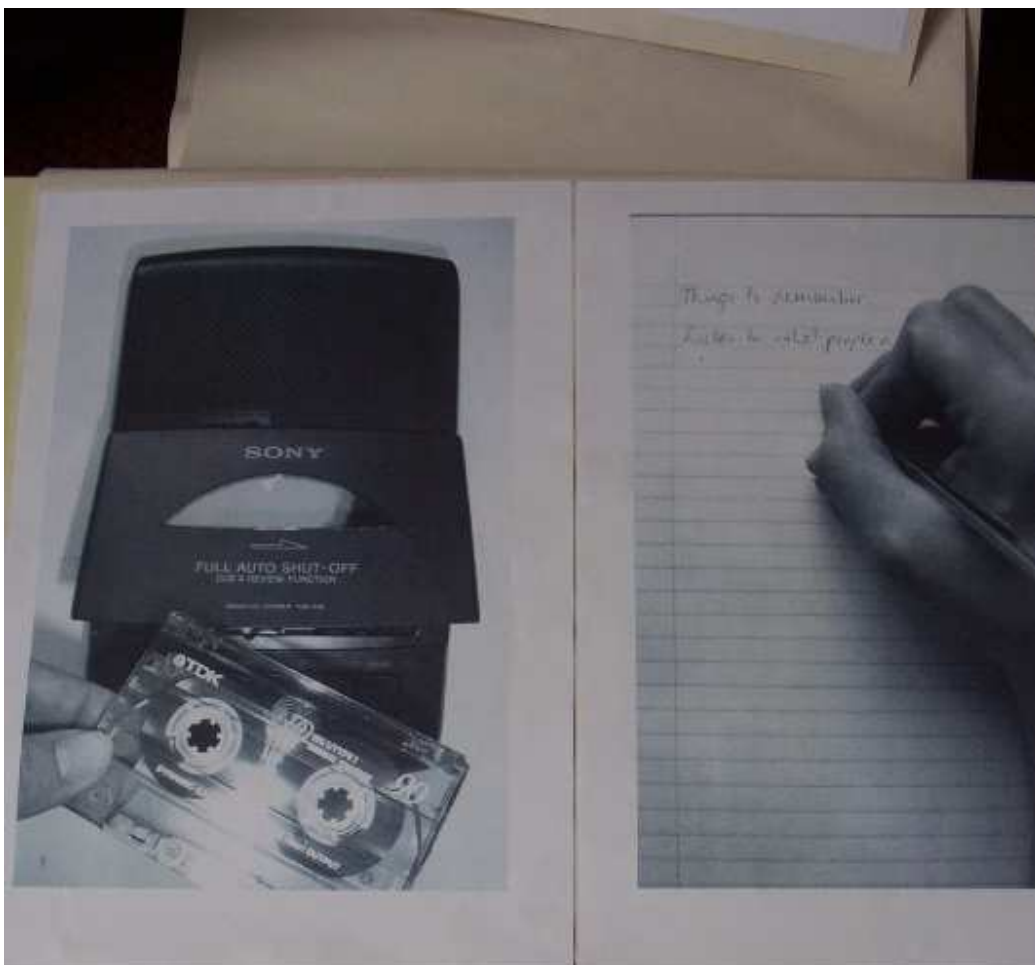


My name is Elizabeth Brace

I am a student at Newcastle University

I'm doing a course called a PhD or Doctor





would record what we said on a tape recorder

I will also write things down.



Especially in relation to sexuality.

Appendix Three  
Handout for respondents

**Hi!**

My name is Elizabeth Brace. I'm doing a course at Newcastle University called a PhD.

[My photograph]

This involves doing research (finding out about things). I am researching about women with learning disabilities like yourselves. I am particularly interested in what women with learning disabilities think about sexuality and relationships.

If you decide to talk to me about these things you will be involved in what is called an 'interview'. This means I will ask you questions and either tape record your answers or write them down. This is important because

[Picture of a lesbian couple hugging]

when I write up my research I will need to remember exactly what you have said! I might interview you more than once to check that I have understood what you have told me and to look at what you have told me in more detail.

There may be some things that you are concerned about. It is important that if you decide to be involved you tell me about these. I will:

- Only talk to you if you want me to
- Stop an interview at any point and for any reason if you want that
- Not expect you to talk to me about things that make you uncomfortable
- Only use the information you have given me if you are happy about me doing this
- Check with you that what you have told me is correct
- Make sure that the information you have given me is kept safe so that only I see it
- Make sure that when I use the information you have given me, nobody will be able to tell that it came from you
- Change your name and maybe the information that you give me so that I can do this

If you decide to take part I will ask you to sign a form saying you agree or will tape you saying so.

Thank you for your interest. Remember that if you have any questions please ask. I can be contacted at The Dept. of Sociology, University of Newcastle upon Tyne, NE1 7RU, Tel. 0191 222 5575 / 0191 222 5576, email [e.a.brace@ncl.ac.uk](mailto:e.a.brace@ncl.ac.uk) or just leave a message with [...] at [...]

## Appendix Four

### Information sheet for parents/support workers

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NEWCASTLE



### *Information sheet for carers*

## Research Project

The title of the research is:

**The influence of institutional processes on women with learning disabilities and their sense of self in relation to sexuality.**

This PhD research is funded by the Economic and Social Research Council and is being conducted within the School of Geography, Politics and Sociology at the University of Newcastle. It is supervised by Prof. Diane Richardson and Dr Janice McLaughlin (who can be contacted at the addresses below).

### Aims of the research

The overall aim of this research is to explore the way in which women with learning disabilities perceive themselves in relation to sexuality. Specific aims include

- ❑ To find out what women with learning disabilities think about their sexuality.
- ❑ To suggest ways in which services can better support women with learning disabilities in relation to their sexuality.

### Methods

#### *Interviews/focus groups with women who have learning disabilities*

These will be with members of a women's group which meets at [...], a voluntary organisation that promotes advocacy for people with learning disabilities.

This part of the research will help me to gather the views of women with learning disabilities which have not yet been well represented within academic research in relation to sexuality.

### *Questionnaires/interviews with care professionals*

These will help me to gather the views of professionals about the ways in which services might influence the way in which women with learning disabilities might perceive sexuality.

### Analysis of current sources of 'formal' information and education on sexuality for adults with learning disabilities

This will involve examining the courses available to people with learning disabilities – both what they cover and how they are delivered.

### Participants who have learning disabilities

Those participants who have agreed to be involved have been invited to take part in focus groups (group interviews), individual interviews or both. The following processes will take place during the period of the women's participation:

- ❑ Participants will have the research explained to them by myself, and during this will be encouraged to ask questions about the research, what their involvement will be and the way in which the information they give will be used.
- ❑ Participants will be provided with a written sheet which they will be encouraged to discuss with friends and/or carers.
- ❑ Participants will be reminded of their right to decline to participate or answer specific questions at any point during their involvement.
- ❑ Confidentiality will be observed at all times and all attempts will be made to preserve anonymity (e.g. names and some details will be changed).
- ❑ Participants will be asked sign (or audio-tape) formal consent to participate. At each stage informal consent will be checked.
- ❑ The research will be supervised.

### How the information will be used

The information will be used for the production of a PhD thesis which will be presented for examination and which will be available publicly. The findings will be made available to participants in a short 'accessible' form via a report. The information may also be used to write articles for academic and professional journals and conferences.

## **Contacts**

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Appendix Five

Focus group and interview consent form

CONSENT FORM

PhD research by Elizabeth Brace of the University of Newcastle-upon-Tyne about women with learning disabilities and their sense of sexual identity.

Please circle the picture that describes how you feel best

Do you understand that you can stop being involved at any time and for any reason without having to explain why? ☺ ☹

Do you understand that the information that you give me will be kept safe so that only I see it, and that I will change your name and maybe the information that you give me so that nobody will be able to tell that it came from you? ☺ ☹

Have you been given a handout about the research? ☺ ☹

Do you feel that you have been able to ask the questions that you would like to about the research and understand what you will be going to do? ☺ ☹

Are you happy to have the focus group/interview taped? ☺ ☹

Are you happy for me to make notes? ☺ ☹

Do you agree to take part in the focus group/interview? ☺ ☹

SIGNATURE OF PARTICIPANT.....

NAME (IN CAPITALS).....



SIGNATURE OF RESEARCHER.....

Appendix Six

## Focus group topic guide

### Initial introduction

Thanks everyone for coming. Over the next hour we'll be talking about sexuality and relationships (who we are close to/how we feel about our bodies and other people's), particularly how we learn about these things. I'll ask a few questions – there are no right or wrong answers and you don't have to answer a question if you don't want to. I'll check every now and again that everyone has had a chance to speak – if you don't want to speak you can just shake your head. As we're meeting as a group it would be great if you could use the questions to talk to one another, not just with me. Remember that you'll be seeing each other after this meeting so don't say anything you'll be embarrassed about later.

(Confidentiality/use of tape recorder already discussed prior when doing consent).

Begin by discussing some 'ground rules' together (briefly) (encourage them to 'own' these) – what we talk about stays within the group/one person at a time – what each person has to say is equally important/no side conversations (use flip chart)

### A) Icebreaker

To begin with I'd like us say our names, and tell each other our favourite colours and why we like them, I'll start...

### B) Where do we learn about sexuality?

- 1) Has anyone been on the [Sex, Love and Relationships] course here at [...], or helped to plan it?  
PROBE: What made you decide to be involved (more information, confidence, being with others)?  
PROBE: Who was involved in that decision – you alone or anyone else?
- 2) And for those of you who didn't, why not?
- 3) Where else do we learn about sexuality? Has anyone got any suggestions?

### USE VISUALS TO EXPLORE

- Parents and family
- Friends/colleagues
- Where you live
- School
- Day services

- College
- Television/cinema/pictures/advertising

Ensure that at least one person is happy with each item on list.

- 4) Looking at these different places, I'd like you all to try and decide which places give us the **most** information.

### C) What do we learn about sexuality?

#### USE VISUALS TO EXPLORE THIS

- 1) Which people or places have given you information on contraception – using condoms or the 'pill' for example (USE LIST)?  
 PROBE: What are people telling you (or not)?
  - About the different kinds of contraception?
  - About how to use contraception?
 PROBE: What kinds of opinions are people giving you (or not) about contraception ?
  - About whether you should be using contraception or not?
  - About the types of contraception are available
 PROBE: Did you want this kind of information or opinion?  
 PROBE: Is there anywhere where we don't talk about contraception?
- 2) Which people or places have given you information on 'fancying' other people - for example the different kinds of relationships you might have and whether they are 'good' or 'bad'?  
 PROBE: What are people telling you (or not) about sex?
  - with men
  - with women – as lovers
  - with yourself – enjoying your own body
  - whether you are with someone for a short time or a long time
  - whether you should be married or not
  - whether they – or you - use a wheelchair or not?
 PROBE: Is there anywhere we don't talk about these things e.g. women with women?
- 3) Looking at these different places where we learn about sexuality, I'd like you all to try and decide where or who **you** would go to for advice? And who do you think you might **not** go to?
- 4) Is there any information that you would like to know about relationships or your/other people's bodies that you don't know about already. I'd like it if we could list these in order of importance – a 'top ten'.

**D) Wind down**

Summarise discussion and ask for comments – what was the most important part of the discussion?

**To end**

Reaffirm confidentiality

Thank them and explain what will happen next (should be interviewing all group participants at future date/ how this will be arranged).

Appendix Seven

**Letter to parent/support worker**

Dear Parent/carers (*use name*)

My name is Elizabeth Brace, and I am a PhD student at Newcastle University. You may have been informed that I am undertaking research, and (*name*) has agreed to take part in that research. The research is being done with the help of the Women's Group at [...] and is an investigation into women with learning disabilities and sexuality. Verbal consent to take part was given by (*name*) at the Women's Group meeting of March 2004. Formal written or audio-taped consent will also be sought prior to any research with (*name*).

So far the research has involved a group interview with 6 people who attend the Women's Group. I am now starting to arrange interviews with the women who have agreed to take part and (*name*) is one of these. The process may involve more than one meeting. I have enclosed a more detailed information sheet about the research.

Because we are focusing on sexuality, (*name*) may ask for information about sexuality or want to talk about the issues she has discussed with me after the interview has taken place. I am liaising with [...] who co-ordinates the Women's Group and she will be available to provide this kind of support, however, your support regarding this would also be greatly valued. *Ask (if manager I'm writing to) to disseminate to staff.* Please do not hesitate to contact me regarding this.

Many thanks in anticipation of your involvement,

Elizabeth Brace

## Appendix Eight

### Interview schedule as of November 2005

#### INTERVIEW SCHEDULE

##### SECTION 1: BACKGROUND

###### **Name/age**

###### **Where you live**

Do you live with anyone else?

(If so) Do you like living with other people/your family?

Was this your choice?

How long have you lived with them?

Would you like to live anywhere else?

(If not), Do you like living alone?

Do you have your own bedroom?

Are you able to decorate your bedroom?

What do you have in your bedroom?

What do you like about your bedroom?

Are you able to lock your bedroom?

Do you get enough privacy?

Do other people knock on the door before they come into your room?

Do staff work in your home?

What do they do?

What's the best thing about your home? What's the worst thing about your home?

###### **Where you've lived before**

(Do a visual 'time line' with participant)

If so, where?

And who with?

Which home did you like best?

And which least?

###### **Your family**

Could you tell me a bit about your family?

Are you close to them?

Who are you closest to?

Do you see your family often?

###### **Activities**

Could you describe a typical week? (Make a chart)

What did you do yesterday?

What did you do last weekend?

What did you do for your birthday?

What's the best thing you do?

And what's the worst thing?  
Is there anything you'd like to do but can't?

**Could you help me to draw a map of your life that includes the places you go to, the people you spend time with and who you are close to? You are at the centre...**

### **Women's Group**

Why do you come to the Women's Group?  
The women's group is for women who are disabled or have learning disabilities. Do you see yourself as disabled?  
What about having a learning disability?

## **SECTION 2: KNOWLEDGE**

### **What does the word 'sex' mean for you?**

Word association?  
If marriage/children are mentioned explore.

Where might you have learnt about (use pictures):  
Having 'sex' (what to do, what it feels like, how to use condoms). Having relationships (finding a partner, how to behave with a partner, feelings/emotions).

(e.g. school, college, books/magazines, TV & internet, parents, friends, staff).

### **Have you talked about sex or relationships with:**

Parents. What did they (or do they) tell you about sex?  
Can you talk to your parents about sex?  
Or other members of your family?  
Can you talk to your parents/family about boyfriends?<sup>178</sup> Can you talk to them about how you feel in relation to these things. Are there things about sex or relationships that you can't talk about with your parents or family?

**Friends.** Do you talk to friends about sex? Or boyfriends?

What do you talk about?  
Are there things about sex or relationships that you can't talk about with friends?

**Staff.** Do you talk to staff about sex? Or relationships?

Which staff?  
What do you talk about?  
Are there things about sex or relationships that you can't talk about with staff?

### **Is it easier talking to women about sex?**

---

<sup>178</sup> The use of 'boyfriend' rather than 'partner' or 'girlfriend/boyfriend' was made after using the schedule and feeling that these latter references might be confusing. After discussion with my supervisors it was felt that 'boyfriend' should be used, but that the schedule, in discussing same-sex relationships, was 'open' enough to allow someone who identified as lesbian, gay, bisexual or queer to say so.

**Have you been on the ‘Sex, Love and Relationships’ course at [...]?**

(If yes) – Why did you go on the course?

What did they tell you about?

Did they tell you about (use pictures/establish understanding):

Relationships? Same-sex relationships? Has anyone else talked to you about this? What did they say?

How to find a boyfriend?

Living together?

Being married? Having children?

Keeping safe?

Contraception? E.g. pills to stop you having babies. What did they say?

Did you learn anything new about sex on the course?

What was the most helpful thing they told you about?

Was there anything they didn’t talk about that you’d like to know about?

(If no) Do you know what kinds of things they talk about on this course?

Did you know about the course?

If so, is there any reason why you didn’t go on the course?

What might make you decide to go on the course?

**Would you like to learn more about sex and relationships?**

**SECTION 3: SEXUALITY/ RELATIONSHIPS**

**Feeling sexy**

Is there anything that makes you feel sexy?

What kinds of things might you do to feel sexy? (Bath/perfume/clothes/make-up/watch a movie/read a book?)

What kinds of things might you think about to feel sexy? (Someone you fancy/ sex/ romantic meal?)

What does that feel like?

Do you ‘fancy someone’? Who? Anybody famous?

What does that feel like?

Have you in the past?

If so, why do you think they are sexy?

**Marriages?**

Are you married?

If so

How did you meet your husband?

How did you come to be boyfriend and girlfriend?

Did you fancy them?

What made you fancy them?

Why did you get married?

What's the best thing about being together?  
What do you like most about your husband?  
What's the worst thing about being together?  
What do you like least about your husband?

If not have you been?  
Would you like to get married?  
What wouldn't you like about being married?  
How is being married different to 'going out' together?

### **Boyfriends?**

Do you have a boyfriend?  
If so, where do you meet?  
When do you meet?  
Is it easy for you to meet?  
Does anything make it difficult?  
How did you meet?  
How did you come to be boyfriend and girlfriend?  
Do you 'fancy' them?  
What made you fancy them?  
What do you do together?  
What makes it easy for you be together?  
Do your friends know your boyfriend?  
Do your friends and your boyfriend get on?  
Do your parents know your boyfriend?  
Do your parents and your boyfriend get on?  
Do you spend time by yourselves, alone?  
When? Where? If not, why not?  
What's the best thing about being together?  
What do you like most about your boyfriend?  
What's the worst thing about being together?  
What do you like least about your boyfriend?  
Have you had a boyfriend before? (see above questions).

### **If you've not had a boyfriend, is this something you think about?**

Have you had a boyfriend?  
Would you like a boyfriend?  
If yes, what would you like about that?  
If not, what wouldn't you like about it?  
If you wanted a boyfriend, what would he be like?  
What kind of person wouldn't you go out with?  
Have you thought about how you might find a boyfriend?  
How would you ask them 'out'?  
What might make it easy or difficult for you to find a boyfriend?

### **Children?**

Have you got children?



If yes, what do you like about having children?  
If not, have you thought about it?  
What would you like about having children?  
Have you ever used contraception, for example, pills to stop you having children?

#### SECTION 4: VIEWS ON SEXUALITY

Is it OK to have sex and not be married?  
Is it OK to have children and not be married?  
Is it OK for a woman to have sex but not be married?  
Is it OK for a woman to have children but not be married?  
Is it OK for a woman to be a 'single mum'?  
Is it OK for women to fancy one another?  
Is it OK for men to fancy one another?  
Is it OK for lesbians and gays to get married?

#### SECTION 5: OTHER PEOPLES' ATTITUDES TOWARDS PEOPLE WITH LEARNING DISABILITIES AND SEX

Do people with learning disabilities have the same chances as other (non-disabled) people to have sexual relationships?  
Do women with learning disabilities have the same chances as men with learning disabilities to have sexual relationships?  
Do people with learning disabilities have the same chances as other (non-disabled) people to get married?  
Do women with learning disabilities have the same chances as men with learning disabilities to get married?  
Do people with learning disabilities have the same chances as other (non-disabled) people to have children?  
Do women with learning disabilities have the same chances as men with learning disabilities to have children?

#### **Finishing Off**

Is there anything important that I've missed that you'd like to talk about?

## Appendix Nine

### **‘Second wave’ interview with ‘Anne’**

#### **Family**

What did your parents tell you about sex or boyfriends?

What about marriage/ having kids?

Would you have liked them to tell you more/less?

Could I ask why your brother’s behaviour didn’t bother your mother (you said it bothered *you*)?

Did you get on with your mother/father?

#### **Home life**

Could you tell me a bit more about where you lived before living here?

Can you remember how old you were when you left your parents’ home?

How did you choose [...] as your carer?

Do you ever have respite care?

What was that like/is that like?

Is it different to living with [...]?

In what ways?

Do you have a key-worker or social worker?

Are you close to them?

Would you consider this person to be a friend?

Would you like to live somewhere else?

If so where and why?

Would you like to live with anyone else? Who with?

#### **Independence/ choice**

Is being independent important to you?

What does independence mean for you?

Do you go out with friends?

Do they visit you at your home?

Do you visit them at their homes?

You said that you don’t travel alone now. Is there any reason for that?

You said that you go to the day service and the women’s group. If you didn’t want to go to these places would that be OK (e.g. with [carer])?

#### **Boyfriends/marriage/kids**

Do you have male friends at the moment?

Would you like male friends?

What's the difference between a male friend and a boyfriend/what do you (or they) do differently when you're with them?

How did you and your boyfriend get together?

What kinds of things did you and your boyfriend do together?

Did you spend time alone together?

What did you like about your boyfriend in [...] What didn't you like?

You'd suggested that he was 'decent but not that decent' when I asked you if he was attractive. Did you fancy your boyfriend – for example his looks?

What, for you, would sex be? I.e. if I said, 'I had sex last night', what would you assume I'd done?

Would you like to have sex/have liked to have sex?

Do you think about sex? Or have you in the past?

Do you listen to what other people might say about their sex lives or relationships?

Do you ever join in with their conversations?

Does [carer] ever talk about *her* partners, boyfriends/husband?

Have you ever talked to [carer] about *your* boyfriend?

Would you like a boyfriend now?

If you would, do you think you would have the chance to meet someone?

Do you think that would be OK with [carer]?

Do you think you would be able to bring him home/spend time alone together?

### **Your body**

Do you like your body?

Does it make you feel good? (mental/physical) How/how not?

### **Same-sex relationships**

What do your family think about same-sex relationships?

Or your friends?

Or staff?

Do you know anybody in this kind of relationship?

### **Talking/learning about sexuality**

Did you learn about sex at school?

Anywhere else?

Who would you feel most comfortable with discussing the kinds of things I've asked you about today?

### **Women**

Is easier talking to women about sexual matters?

**The organisation where the women meet**

You said that you'd been on a couple of the courses at [...], which ones?

You haven't been on the 'Sex, Love and Relationships' course, would you like to?

Why/why not?

## Appendix Ten

### Information sheet given to the facilitator of the *Sex, Love and Relationships* course



### *Research information sheet*

## Research Project

The title of the research is:

**The influence of institutional processes on women with learning disabilities and their sense of self in relation to sexuality**

This PhD research is funded by the Economic and Social Research Council and is being conducted within the School of Geography, Politics and Sociology at the University of Newcastle. It is supervised by Prof. Diane Richardson and Dr Janice McLaughlin (who can be contacted at the addresses below).

### Aims of the research

The overall aim of this research is to explore the ways in which social care services at national, local and institutional levels – including sources of formal information and education on sexuality – influence the way in which women with learning disabilities perceive themselves in relation to sexuality. Specific aims include

- ❑ To find out what women with learning disabilities think about their sexuality, and how they think services might affect that.
- ❑ To find out how services are currently provided.
- ❑ To suggest ways in which services can better support women with learning disabilities in relation to their sexuality.

### Methods

*Interviews/focus groups with women who have learning disabilities*

These will be with members of a women's group which meets at [...], a voluntary organisation that promotes advocacy for people with learning disabilities.

This part of the research will help me to gather the views of women with learning disabilities which have not yet been well represented within academic research in relation to sexuality.

#### *Questionnaires/interviews with care professionals*

These will help me to gather the views of professionals about the ways in which services might influence the way in which women with learning disabilities might perceive sexuality.

#### Analysis of current sources of 'formal' information and education on sexuality for adults with learning disabilities

This will involve examining the courses available to people with learning disabilities – both what they cover and how they are delivered.

#### How the information will be used

The information will be used for the production of a PhD thesis which will be presented for examination and which will be available publicly. The findings will be made available to participants in a short 'accessible' form via a report. The information may also be used to write articles for academic and professional journals and conferences.

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## Appendix Eleven

### Details of *Sex, Love and Relationships* course participants, facilitators and support workers

Table 5: *Sex, Love and Relationships* course participants, facilitators, planners and support workers: attendance over the five weeks of the course

| Week | Staff                      | Planners   | Attendees  | Support workers for:      |
|------|----------------------------|--|--|---------------------------|
| 1    | 'Derek'(m);<br>'Susan'(f). | 'Kath'(f);<br>'Colin'(m);<br>'Paul'(m).          | 'Ben'; 'Angie'; 'Eric';<br>'Vicky'; 'Glen'; 'Jan'.             | 'Jan'; 'Ben'.             |
| 2    | 'Derek'(m);<br>'Lucy'(f).  | 'Kath'(f);<br>'Colin'(m);<br>'Paul'(m); Neil(m). | 'Ben'; 'Angie'; 'Eric';<br>'Vicky'; 'Glen'; 'Jan';<br>'Henry'. | 'Jan'; 'Ben'.             |
| 3    | 'Derek'(m);<br>'Susan'(f). | 'Kath'(f);<br>'Colin'(m);<br>'Paul'(m); Neil(m). | 'Ben'; 'Angie'; 'Eric';<br>'Glen'; 'Jan'; 'Henry'.             | Unknown.                  |
| 4    | 'Derek'(m);<br>'Susan'(f)  | 'Kath'(f);<br>'Colin'(m);<br>'Paul'(m).          | 'Ben'; 'Angie'; 'Eric';<br>'Vicky'; 'Glen'; 'Jan';<br>'Henry'. | 'Ben'; 'Jan';<br>'Henry'. |
| 5    | 'Derek'(m).                | 'Kath'(f);<br>'Colin'(m); 'Neil'<br>(m).         | 'Ben'; 'Angie'; 'Eric';<br>'Vicky'; 'Glen'; 'Jan';<br>'Henry'. | 'Ben'; 'Jan';<br>'Henry'. |

(m) = male; (f) = female.

There were seven participants on the course overall: Ben (male, twenties), Angie (female, thirties), Eric (male, mid-fifties), Vicky (female, twenty-nine)<sup>179</sup>, Glen (male, thirties), Jan (female, forties) and Henry (male, fifties). The participants did not know each other prior to the course. There were two course facilitators each week (excluding the final week when the main course facilitator ran the course alone): the main course facilitator (Derek, male, forties) attended each week, a female course facilitator (Susan, early thirties) attended for three of the weeks and another female course facilitator (Lucy, early thirties) attended one of the weeks. There were also four volunteers with

<sup>179</sup> Vicky subsequently became an interviewee – I approached her when she decided to start attending the women's group.

learning disabilities, who were also members of the planning team<sup>180</sup> (Kath, female, mid-fifties; Colin, male, mid fifties; Paul, male, mid-fifties; Neil, male, early thirties). All the planners knew each other from previous voluntary work with the centre. Kath and Colin attended all five sessions, whereas Neil attended three and Paul attended four. Although Susan (facilitator) and Paul and Neil (planners) did not attend all the sessions, this did not appear to affect how the course was run. Although most of the planners were older men and women, this reflected the relatively high age of the participants and did not seem to impact on course content. Some of the participants also had support workers with them. Some participants' support workers changed each week<sup>181</sup>. Although support workers were of the same sex and appeared to be of a similar age to Jan and Henry, Ben's support workers seemed to be aged from around thirty to fifty (Ben was around twenty), and on one occasion he was supported by a woman in her late forties<sup>182</sup>. Support workers were encouraged to participate where appropriate if they sat within the group<sup>183</sup>. One support worker chose to sit outside of the group but did make comments when invited to during the evaluation<sup>184</sup>. Ben's support workers prompted him quite frequently in discussions, and although this was done in a supportive and respectful way, it might have influenced how and what he contributed to the sessions.

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<sup>180</sup> The *Sex, Love and Relationships* course as well as other courses at the centre has a planning team consisting of paid course facilitators (none of whom were disabled on this occasion) and volunteers (who may or may not be disabled). When critiquing this course it is important to remember that the course is not developed by non-disabled people *for* people with learning disabilities, but purposely includes people with learning disabilities on the planning team.

<sup>181</sup> This lack of consistency might make it difficult for participants to feel comfortable when discussing sexuality, and suggests perhaps that either consideration had not been made by support staff in this respect, or that staffing levels did not allow for it (see Chapter Three).

<sup>182</sup> I would suggest that the best support might be from someone of the same sex and a similar age, *however*, Ben might have been happy for any or all of these carers to support him, and might not have been concerned about their age or sex.

<sup>183</sup> Some did and some did not. I would suggest that not taking part underlined the support worker/service user divide given the encouragement for support workers to participate.

<sup>184</sup> When I asked the main course facilitator about how he felt about support workers staying with participants on the course, given the subject matter and the possibility that support workers' presence might make it difficult for participants to discuss it, he suggested that this was the participant's decision, but otherwise and *ideally* support workers would leave the room (but be available in the building should they be needed).



## Appendix Twelve

### ***Sex, Love and Relationships* course: fieldnotes from day one – ‘What is sex’?**

#### **What is sex?**

##### **(Divided into male/female groups to discuss)**

Re: ‘what is sex’, women said the following (in word shower) –

Contraception, condom, Femidom, Depo, pill, coil, vibrators, pregnancy, hard, stiff, change of life, womb, eggs, cervical screening, health, 2 people getting together, men/women, 2 women, 2 men, sometimes don’t want, sometimes rushed, only in private, in the pictures, sex in different places, children shouldn’t know about sex until they’re 18, law says sex OK at 16, law says sex OK at 18.

When groups got back together ‘Neil’ (volunteer) pointed out that the women hadn’t seen sex as ‘dirty’ or something to be ashamed of (the men had).

‘Lucy’ (facilitator) pointed out to the women that they hadn’t mentioned orgasm (their responses suggested that they knew what this was).

Generally a strong slippage into health/safety? (Contraception was mentioned first.) Idea of homosexuality brought up easily and without comment. Notable that sex involves 2 people for some although use of a vibrator – to be used alone – was mentioned. Sex as not just a penetrative act.

The men’s group came up with:

Relationship, 2 in a bed together, birds and bees, kissing, touch in bed, intercourse, time in private, oral sex, dancing, singing together, flirting, condoms (‘French letters’) (sometimes), safer sex, Femidoms, the cap, making people feel good about self, ‘get off’, going out with different partners, might blush/go red, gay, lesbian, bi, straight, choice is important.

Like women, they missed off orgasm.

Not a negative thing (women – ‘rushed’, ‘sometimes don’t want’) but something you could feel embarrassed about (not mentioned by women). Like women they included contraception. Mention how you’d interact with another person sexually (make them feel good/choice) (women didn’t). Also described more what you would do – kiss, touch, oral sex.

## Appendix Thirteen

### ***Sex, Love and Relationships* course: fieldnotes from day five – course evaluation**

Although I had informally talked to 3 or 4 people during the day, this evaluation was comprehensive, and what people said ‘officially’ mirrored what people had said in private. ‘Derek’ (facilitator) asked why people thought it was important to evaluate the course. ‘Glen’ said ‘so you can do it better’ – agreed by ‘Derek’ who said that everyone’s comments would help the planners when they next ran a course. During this section ‘Derek’ tried to make a distinction between participants and planners and carers – ‘Neil’ (planner) tended to answer when the participants were being asked their opinions and several times ‘Derek’ reminded him to let the participants have a chance to speak.

#### **What was learnt/what was good:**

‘Jan’: ‘all the course was great’.

‘Glen’: ‘when Freda came to talk about sex and that’ (nurse).

‘Glen’: the video (*Eileen’s choice*), ‘it was good when she went to buy condoms and tried them on a courgette’.

‘Jan’: commented on the bit in *Eileen’s choice* [film] when her ‘mum said she was too young to have a boyfriend’ and described how Eileen introduced her boyfriend to her mum, which was ‘a shock’ but ‘she got to like him’. ‘Derek’ also pointed out that she got help from her carer/social worker.

‘Jan’: said that she’d learnt about contraception and sex, ‘our bodies’ and ‘masturbating’.

‘Henry’: mentioned ‘erections and orgasms’.

‘Jan’: ‘we talked about our penises and vaginas’. She went on to say ‘I hope that doesn’t embarrass you lads’.

‘Angie’: suggested that ‘the lads might not want to talk about our bits’.

‘Angie’: ‘spunk’.

‘Glen’: ‘you cannot force anyone to have sex’.

‘Derek’ pointed out that ‘sex is about lots of different things’,

‘Jan’: ‘intercourse and anal sex’.

‘Vicky’: ‘new friends’.

‘Vicky’: the role play was ‘good and funny’.

‘Jan’: The role play was quite good, it was excellent’.

‘Henry’: ‘What we feel and that’. Derek thought he said [the name of the nurse who did a session with the group], and the conversation turned to the time when the nurse came and ‘Angie’ said ‘I thought that was good as well’.

‘Henry’ also said of the role play ‘it was quite good’.

‘Eric’: liked people getting dressed up as other people. When Derek asked if this helped people learn ‘Angie’ said ‘no’. However, despite refusing to take part ‘Angie’ said that she would like to have done more role play!

‘Ben’ said that he had a girlfriend, and they didn’t have sex ‘no way’ because he couldn’t get condoms. If he had condoms he would have sex. ‘Derek’ suggested that this might be something he might ask for help with when he went home. Issue of what happens after the course raised by ‘Derek’ later.

‘Angie’: ‘I enjoyed it’ and liked the video.

‘Glen’: enjoyed meeting new friends.

‘Jan’: agreed.

### **Was there anything that wasn’t talked about but should have been?**

‘Glen’: ‘No, fine’.

‘Neil’: suggested ‘bullying’. ‘Derek’ asked if he meant ‘abuse and harassment’. ‘Neil’ agreed and ‘Derek’ reminded him that this had been covered but that ‘maybe we need more time on abuse’. ‘Angie’ agreed.

‘Henry’: suggested more in-depth information and details (maybe a little to slow for him?).

Re course length, ‘Neil’ and ‘Angie’ agreed that 5 days was a good course length. ‘Eric’ commented that ‘five’s enough for me’.

### **What could be better?**

‘Kath’ & ‘Glen’ – cakes!

‘I think it was all good, I can’t think of anything that could make it better’ (‘Jan’?).

‘Henry’: leaflets and handouts.