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(S)exploring Disability

Intimacies, Sexualities and Disabilities,

Kirsty Liddiard MA

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This thesis is dedicated to Jacky Lee 1946 – 2011 who never got to read the final draft.

You are the determination in every page.

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Declaration

I declare that this thesis contains my own research performed under the supervision of Dr Carol Wolkowitz and Dr Karen Throsby, both of the Department of Sociology, University of Warwick. I confirm that this thesis has not been submitted for a degree at another university.

Abstract

This thesis details an empirical exploration of disabled peoples' lived experiences of sexual and intimate life. Disabled people are predominantly desexualised and degendered and within ableist cultures; they are also, as Brown (1994: 125) states, assigned paradoxical social categories of 'asexual, oversexed, innocents, or perverts'. Thus, this thesis begins from the position that disabled peoples' access to and experiences of sexual life occur in the context of these dominant ableist constructions of disabled sexualities, and that the reclamation or formation of a sexual self requires resistance to, or strategic management and negotiation of such constructions.

The research methodology worked to the central tenets of consultation, accessibility, empowerment and relevance. A Research Advisory Group made up of local disabled people was established, the purpose of which was to guide the research process, offer expert knowledge, and ensure that the research was accessible, engaging and empowering for the individuals who took part. Through a thematic analysis of the sexual stories told by twenty-five disabled people (and one non-disabled partner), in their own words and on their own terms, this thesis details the complex and variegated relationships between disability, impairment, sexuality, and gender.

Findings show that heteronormative discourse had very complicated and contradictory implications for disabled men and women, but also empowered disabled men relative to disabled women. Moreover, analysis has illustrated the 'complex invisible "work" performed by disabled people' (Church et al 2007: 1) through participants regularly taking on the roles of teacher, negotiator, manager, mediator, performer, educator, and resistor within a variety of spaces in their sexual and intimate lives. While this work was evidence of sexual agency, the majority of participants' labours were rooted in the oppressive and inherent inequalities of ableist culture. Furthermore, the majority of participants experienced extensive psycho-emotional disablism – 'the socially engendered undermining of psycho-emotional wellbeing' (Thomas, 1999: 60) – as routine within their sexual and intimate lives.

(310 Words)

Introduction

This thesis details an empirical exploration of disabled peoples' lived experiences of sexual subjectivity and intimate relationships. Disabled people have 'a sexual history characterized largely by oppression and discrimination' (Rembis 2010: 53), and much of this sexual history has, in the past, been overlooked within both academic and activist contexts in favour of a focus on disabled peoples' social and political histories (Shakespeare et al 1996; Finger 1992). Through disability rights movements from the 1960s onwards, disabled people have fought for their rightful place within civil and public life, campaigning for: civil rights; anti-discrimination legislation; equal access to education; community integration, and environmental accessibility. Characteristically, alongside this have been an appreciation of diversity and a vivid celebration of pride. This (necessary) structural focus upon disabling environments has left disabled peoples' sexual politics marginalised and thus has inadvertently created a significant dearth of knowledges around disabled peoples' private and intimate lives. However, since the work of some disabled activists who have powerfully spoken out about their sexual oppression as central to their dehumanisation (see Finger 1992), and the influential text *The Politics of Disabled Sexuality* (Shakespeare et al 1996), explorations of the oppressions within disabled peoples' intimate lives have emerged, albeit slowly. Through a thematic analysis of the sexual stories told by twenty-five disabled people (and one non-disabled partner) in the UK, in their own words and on their own terms, this thesis contributes to this emerging body of knowledge. In this introduction I further contextualise the research and outline its specific areas of inquiry while providing a thorough overview of what will follow in this thesis.

Constructed (A)sexual Selves

Disabled people are desexualised and degendered, and considered 'sexually dead' (Hooper 1994) within ableist cultures. Until recently they have been defined predominantly as *asexual*, as lacking any sexual feeling and desire. Alternatively, they are defined as sexually inadequate or as sexual victims and objects of fetish: the assumption that their only experience of the 'sexual' is through sexual violence and abuse and through 'devotees' (who themselves are pathologised for their sexual attraction to impairment). Paradoxically, disabled people can also be considered sexually deviant through requiring non-normative sexual practices such as facilitated sex and sex work. These acts of 'immorality' are considered further deviant because, to fit with ableist constructions of 'disability' as passive, vulnerable and childlike, disabled people aren't supposed to be having or desiring sex at all. Crucially, for this thesis, disabled people are considered to lack the attribution of sexual *agency*:

> 'Disabled people are often not allowed to have agency, sexual or otherwise. Rather they are pictured as abject beings, close to nothing, empty husks. To be disabled in the cultural imaginary is to cease to function' (Siebers 2008: 160).

The above, are the dominant *ableist* constructions of sexuality that are ascribed to disabled peoples' lives and bodies. For the purposes of clarity, I use Campbell's (2001: 44) definition of ableism throughout this thesis:

> 'A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human.

Disability then is cast as a diminished state of being human.'

Such constructions are ascribed to disabled people primarily because of the inherent medicalisation of their lives and bodies. Medical models of disability forcefully prevail in Western cultures. Such models perceive and treat impairment as physiological deficiency and social 'tragedy' which at best requires relentless (and painful) classification, intervention and treatment, and at worst, eradication. For example, Morris (1990) proposes that restricted access (for disabled people) to sexual health services and family planning (Waxman 1994), legal abortions on disabled foetuses at any time of gestation, much genetic and stem cell research, and more recent 'end of life' debates (Rock 1996; Morris 1991; Sobsey 1994) are contemporary forms of genocide. Thus, the impaired body and disabled existence are firmly devalued and dehumanised within medico-scientific contexts and are subject to unquestioned medical-management and intervention. Therefore, the medical paradigm extends the impaired 'broken body' (Morris 1991) a very different set of priorities than a body without impairment and because of this it is considered as not requiring or incapable of embodying sensuality, pleasure and desire (Tepper 2000).

Oppressive constructions of disabled peoples' sexual selves are also rooted in Western conceptualisations of sex. The heteronormative sexuality to which the majority aspire is a distinctly narrow mode of *naturalised* sexuality which is largely genitally-focused and performance-orientated (Tepper 2000). Disabled people are assumed to lack the bodily requirements to perform heteronormative sexuality and their alternative means of acquiring pleasure often remain unrecognisable; as Siebers (2008: 133) contends, such 'illiteracy about the minds and bodies of disabled people drapes their sexual practices in deviance and perversion'. While I propose that

heteronormativity is oppressive for *all* people, particularly women, I seek to understand the ways it in which it is related to notions of ableness, serving to exclude and oppress people with impairments (and many others) whose sexual practices may deviate from its prescriptions.

Disabled Sexualities in Popular Culture

In recent times the notion of disabled people as *sexual* has started to appear within the (mainstream) public consciousness more than ever before. For example, we are seeing cultural representations of disabled people on television which are considerably different to existing stereotypical representations which serve only to objectify disabled characters and their impairments (e.g. *Cast Offs*, Channel 4 2009; *Britain's Missing Top Model,* BBC 2008). Moreover, disabled peoples' recent claims for sexual citizenship means their sexual politics are now at the forefront of many disability rights movements in the UK (e.g. The Outsiders' *Respect Tool Kit*; The Sexual Health and Disability Alliance Campaign; Leonard Cheshire Disability's *In Touch*), and are included in the agendas of mainstream charities and organisations (e.g. Family Planning Association's *It's My Right!* Campaign; Brook's *Sex and Disability*). However, at the same time, prevailing oppressive definitions of disablement are ever-present within postmodern society where neo-liberal and scientific rationalist ideologies are thriving and, particularly, where current global austerity measures are highlighting the *costs* and therefore undermining the value of disabled people.

Therefore, while such movements to 'humanise' and embody disabled peoples' lives within the non-disabled gaze are, I suggest, taking place, one must not forget that such developments remain set against the background of an inherent ableist

culture which propagates compulsory 'ableness', therefore simultaneously devaluing disabled peoples' existence (Campbell 2009). The current UK context is a good example of an ableist culture; for example, many disabled people live in continuing poverty (Parckar 2008); many remain excluded from or poorly supported and protected within the labour market (Wilton and Schuer 2006); disability hate crimes are seldom satisfactorily recognised and policed (Roulstone et al 2011); disabled foetuses are denied the protection of non-disabled ones (past 24 weeks gestation) (Shakespeare 1999; Bailey 1996); assisted suicide laws remain elusive and based upon dangerous ableist assumptions about 'quality of life' (Koch 2000), and 'eugenetics' movements (Armer 2007) and 'genetic fundamentalism' (Overboe 2007: 223) are at the forefront of biomedical science research. Thus, while we are seeing a cultural expansion of the category of 'disabled' within popular culture, particularly with regard to sexual and 'adult' life, such changes remain embedded within ableist conceptualisations of disability, impairment, and normative sexuality.

Recent Empirical Studies of Disability and Sexuality

Shakespeare, Davies and Gillespie's (1996: 1) text on disability and sexuality, *The Politics of Disabled Sexuality*, was 'the first book to look at the sexual politics of disability from a disability rights perspective'. The distinctly atheoretical text (Shuttleworth and Sanders 2010) for the first time voiced disabled peoples' own sexual stories. Prior to this, very little empirical research on disability and sexuality (from a disability rights perspective) had been carried out; rather, attention to disabled peoples' sexual lives could be found within 'medical, psychological and sexological backgrounds' (Shakespeare et al 1996: 3). This is why even today, in comparison to other areas of inquiry, sexual and intimate life remains an under-

researched and under-theorised space within disabled peoples' lives. There have, however, been a few attempts to commence a dialogue about the sexualities of disabled people as early as the 1980s; for example, Hicks' (1981: 79) assessment of 'sexual problems and visual impairment' within Brechin, Liddiard and Swain's (1981) *Handicap in a Social World,* itself a leading early disability text which offered a thorough overview of the diverse areas of disabled peoples' lives. Shakespeare et al's (1996) critique of the existing qualitative studies of the time centred on the ways in which such research discussed disabled peoples' married lives but left the sexual distinctly unattended (see Parker 1993; Seymour 1994).

Later, the mid 1990s saw the beginnings of empirical research into disabled peoples' intimate lives which looked at the social 'barriers' to disabled peoples' sexual expression. For example, areas of focus were sexual life (Sakellariou 2006; Pearson and klook 1989; Shakespeare 2000; Shakespeare et al 1996; Dune and Shuttleworth 2009; Bonnie 2004; Crabtree 1997; Tepper 2000; Eunjung 2011; Waxman-Fiduccia 2000; Guldin 2000; McCabe et al 2000, 2003), sexual and reproductive health and family planning (Browne and Russell 2005; Welner 1999; Wong 2000; Anderson and Kitchen 2000), sexual rights (Abeyesekera 1997; Petcheskey 2000), parenting/motherhood (Kent 2002; O'Toole 2002; Prillelltensky 2003), sexual identities (Galvin 2006; Scherrer 2008), disabled sexualities in other cultures (Addlakha 2007a; Yoshida et al. 1999; Cheausuwantavee 2002; Kohrman 2008; Li and Yau 2006; Villanueva 1997; Wazakili et al. 2006), disabled mens' experiences (Tepper 1999; Shuttleworth 2000; Blythe and Carson 2007; Ostrander 2009; Shakespeare 1999) and disabled women's experiences (Bryant and Schofield 2007; Howland and Rintala 2001; Rintala et al 1997; Leibowitz 2005; Mona et al

1994; Parker and Yau 2011). Investigations surrounding the sexual (and other) forms of abuse of disabled people has also been prevalent: for example, intimate partner abuse (Hassouneh-Phillips and McNeff 2005), prevalence of abuse (Young et al 1997), barriers and strategies in addressing abuse (Powers et al 2002), (sexual) vulnerability (Nosek et al 2001; Milberger et al 2003; Hollomotz 2010), and care-related violence (Hassouneh-Phillips and McNeff 2004). Finger (1992: 3) argues that a specific focus on abuse 'can itself become oppressive', and, paradoxically, despite the extent of such knowledge, disabled people remain 'losing out in both counts' through having a greater need for violence and abuse services coupled with far less specialist (and accessible) provision (Thiara et al 2011).

Thus, there is 'still a marked lack of innovative socio-political and cultural research in disability and sexuality' (Shuttleworth 2010: 4), with the following areas of disabled peoples' sexual subjectivities being routinely overlooked:

> 'Much less investigated are the socio-political structures and cultural meanings that restrict disabled people's sexual expression and sexual opportunities, disabled people's modes of resistance and creative sexual agency in their search for sexual wellbeing, the sexual implications of the intersection of disability with identity categories such as gender, race and sexuality, the impact of different policy contexts on disability and sexuality issues, and other topics less concerned with normative functioning.' (Shuttleworth 2010: 3)

When Shuttleworth (2010: 3) refers to 'creative sexual agency' he is referring to the absence from existing research of 'detailed descriptions of disabled people's actual sexual activities, how they, in fact, often do adapt their impairments using different

positions and various sexual aids to facilitate sexual fulfilment' (see also Hamam et al 2009). Additionally, echoing the assumed heterosexuality of disabled people (Siebers 2008) (where they are avowed a sexual self), is the absence of research into the (sexual) lives of disabled people who identify with gay, lesbian, queer and BDSM sexualities (Appleby 1994; Corbett 1994; Courvant 1999; Davies 2010; Whitney 2006; Davie 2010; Tremain 2000; Brownworth and Raffo 1999). Furthermore, while there are notable exceptions (see Gillespie-Sells et al 1998), there is little exploration of disabled peoples' intimate relationships; for example, their interpersonal relationships with (sexual) partners and experiences of intimacy and love. Another significantly under-researched area, possibly because its ability to 'evoke highly emotionally charged discussion within, without and across the disabled and non-disabled communities' (Kanguade 2010: 207), is disabled peoples' use of sex workers (Sanders 2007) and their engagement in forms of facilitated sex. Sanders (2010: 152) calls for 'research into the moral, social, practical, financial, legal and emotional dynamics of buying a sexual service for people with impairments'; particularly the ways in which local policies impact upon disabled peoples' accessing of sex workers and sex facilitation (Earle 1999; Davies 2000) and the 'ethical dilemmas surrounding political and structural barriers to implementing sexual facilitation services' (Shuttleworth 2010: 4).

Research Questions

While my descriptions of the ableist sexual constructions of disabled people remain somewhat pithy in this introductory chapter, they are fully explained, problematised and deconstructed throughout this thesis. My purpose for outlining them at this juncture is to provide a context for the following research questions and

establish the position from which this thesis begins: that disabled peoples' access to and experiences of sexual life occur in the context of dominant ableist constructions of disabled sexualities, and that the reclamation or formation of a sexual self requires resistance to, or strategic management and negotiation of such constructions.

- **How do disabled adults experience sexual opportunities, identities, and intimate relationships?**

This question focuses my inquiry primarily on disabled peoples' lived experiences of a range of areas of their sexual subjectivities: their sexual opportunities and encounters, their construction of a sexual identity and self, and their experiences of intimate relationships with others. My interest here is to explore the wide-ranging means through which disabled people experience sexual life, and the possible non-conventional routes that this may take within a culture where opportunities for sexual expression are restricted for many disabled people. Part of this exploration centres on the ways in which disabled people experience their cultural desexualisation. Thus, how they understand 'the socio-political structures and cultural meanings that restrict disabled peoples' sexual expression and opportunities' (Shuttleworth 2010: 3); because whether limited sexual opportunities are understood and experienced as individual failure or as a mode of social oppression is crucial towards the shaping and extent of possible forms of resistance and/or negotiation.

- **What strategies do disabled adults employ in order to manage and negotiate their sexual lives?**

This question relates directly to the agency and autonomy that disabled people can exercise in forming their sexual identities, pleasures, practices, desires and relationships. I want to examine not only what *impact* ableist constructions of

sexualities may have on disabled peoples' sexual selves, but also the ways in which disabled people may resist, manage and negotiate their sexual subjectivities. Also in focus is the manoeuvrability that disabled people can exercise within existing normative sexual and gendered categories. My interest here is not on 'disabled people's sexuality as a problem to be solved at the level of the individual' nor solely on 'individual adjustment to one's impairment' (Shuttleworth 2010: 3) which has been the focus of the majority of research on disabled sexualities. Rather, my focus is upon the extent to which disabled people have the ability to resist, transgress, manoeuvre, and expand both conventional sexual categories and the ableist ascriptions through which they are desexualised.

- **What are the psycho-emotional consequences of ableist constructions of sexuality for disabled people, and what are the psycho-emotional consequences of their own strategies?**

This question also relates to disabled peoples' experiences, but by using the term psycho-emotional I am referring to 'the socially engendered undermining of psycho-emotional wellbeing' (Thomas, 1999: 60) that disabled people can experience in ableist cultures. Reeve (2002) and Thomas (1999) use this term with specific reference to a relational form of disablism embodied through experiences of 'hostility or pitying stares, dismissive rejection, infantilisation, patronising attitudes, altruism, help and care on the part of non-disabled people' (Goodley 2010: 96). Thus, my focus here is on how ableist constructions and wider sexual oppression *feel* for the disabled participants who are its subject. I concentrate on sexual self-esteem, bodily esteem, confidence, feelings of self-worth and value, and self-belief in relation to intimate life. Thus, my interest is in how participants manage these

feelings, and how it impacts upon their sexual self and intimate relationships.

Thesis Contents

Here, I will give an overview of the thesis content to provide a 'road map' for the reader. Following a detailed chapter outlining the theoretical foundations underpinning my research and an explanation of methods, the thesis is organised into four data chapters which detail distinct analyses of the multiple areas of disabled peoples' sexual lives: experiences of negotiating a sexual self within the public sphere; experiences of intimate relationships; experiences of sexual life and the management of impairment, and experiences of commercial and non-commercial facilitated sex. The thesis ends with a conclusion which sets the key findings within the wider context of disabled peoples' lives.

Chapter 2: Theorising Disabled Sexuality: Constraints and Possibilities

This chapter provides a theoretical background for my empirical investigation, and poses a number of key questions. I set out my rationale for adopting a theoretical stance typical within emerging critical disability studies, incorporating a myriad of critical social theories such as feminism, interactionism, phenomenology, post-structuralism, queer, postmodern and psychoanalytic approaches to disability, gender, sexuality, identity, embodiment and subjectivity. I first concentrate on the problems and possibilities in theorising dis/ability. I discuss the ways in which the social model of disability is unable to adequately inform the exploration of disabled sexualities and outline my more critical conceptualisation of disablement. Next, through the need to fully theorise impairment as a social and cultural construct, I examine critical approaches which radically redefine impairment and the impaired

body. In the second half of the chapter I turn my focus to writings on sexuality and consider the application of biological, post-structuralist, interactionist, and queer perspectives to disabled sexualities and examine how these different lenses, and their often-conflicting viewpoints, support my specific areas of inquiry. The chapter concludes by questioning whether critical social theories as currently constructed can adequately theorise the lived and embodied realities of disabled peoples' sexual and intimate lives.

Chapter 3: Methodology

The methodology introduces the overarching interpretivist epistemology and constructivist ontological framework within which the research is located. The first section of this chapter outlines the research design. It explains the reasons for diverging from a strict adherence to emancipatory or participatory approaches to disability research which were created to try to ensure social research be less 'parasitic' (Hunt 1981) and more empowering for the disabled people at its core. Instead, I state the ways in which the research design worked to the identifiable central tenets of such approaches, making a commitment to consultation, accessibility, empowerment and relevance. For example, I outline the merits of consulting with disabled people through the establishing of a Research Advisory Group; the benefits of ensuring that the research process be truly accessible for disabled participants; the notion of story-telling as an empowering act (see Plummer 1995), and the necessity to keep the research and its findings relevant and meaningful to disabled people both inside and outside of the academy. Following this, I detail the ways in which participants were accessed and sampled, and offer a detailed overview of participants and a thorough explanation of the collection and

analysis of disabled peoples' sexual stories. The final part contemplates the imperative ethical considerations required and features a reflexive discussion of my own subjectivity as a white middle class disabled woman carrying out research of this kind, and the practical and emotional challenges it entailed.

Chapter 4: 'Public' Sexual Selves

The analysis of data begins by providing an introduction to the explication of findings which follow by examining disabled participants' experiences of managing and negotiating a sexual identity in the public sphere. My analysis shows that participants' concerns about an ascribed (a)sexual identity occurred within particular social spaces and processes; for example, through experiences of sex education and adolescent sexual cultures, through their routine experiences of lacking privacy and autonomy, and through their experiences of voyeurism in different social contexts. I explore these spaces with reference to the forms of management and negotiation disabled participants' carried out in order to carve out their desired public sexual self and identity. I situate this analysis broadly within Plummer's (2003) concept of 'intimate citizenship' and question the ways in which disabled peoples' ascribed asexual identities contribute to their lack of rights to intimate citizenship.

Chapter 5: The Intimate Relationship as a Site of Emotional Work

This chapter explores participants' experiences of current and past intimate relationships. I use Hochchild's (1983) concept of 'emotional work' to identify the various forms of work and performances which were required of disabled partners in order to mediate tensions at specific sites within their intimate relationships. Crucially, throughout these stories disabled people cast *themselves* as active subjects,

workers, managers, and facilitators of their intimate relationships, resisting dominant constructions of disabled people as passive, unproductive and worthless. Significantly, the chapter highlights that the intimate relationship is a social space not devoid of the hierarchies, inequalities and oppression experienced by disabled people in public life. However, analysis shows that this was seldom acknowledged by disabled participants who utilised the intimate relationship as a space through which to affirm gender identities, gain sexual self-confidence and esteem, and avoid discrimination and prejudice. The chapter ends by questioning the psycho-emotional consequences and costs of carrying out such emotional work.

Chapter 6: The Impaired Body and Sexual Normativity

This chapter explores how the sexual pleasures, practices, and interactions of disabled people are shaped by both their 'anomalous embodiment' (Shildrick 2009) and dominant discourses of heteronormative sexuality. The analysis problematises heteronormative sexuality specifically with reference to impaired bodies and considers how bodily factors that may be experienced as a result of impairment interact with the conventionally gendered sexual identities and practices of disabled men and women. Analysis showed that disabled participants accepted, resisted, and negotiated dominant discourses of heteronormative sexuality through a variety of means. Furthermore, while the reality of the impaired body was found for many to be a barrier towards achieving normative gendered sexual practices, this simultaneously was a site where 'creative sexual agency' (Shuttleworth 2010: 3) could be exercised to produce new possibilities, pleasures and methods (specific to the impaired body) and redefine traditional (oppressive) gender identities. However, this was often

seldom understood in positive terms by disabled participants, many of whom positioned their alternative sexual practices as 'Other'.

Chapter 7: Going Over to the 'Dark' Side: Experiences of Commercial and Non-commercial Facilitated Sex

This chapter focuses on participants' experiences of commercial facilitated sex and, to a lesser extent, their experiences of non-commercial facilitated sex. I explore the experiences of participants who engaged in these practices and those who did not, in order to capture the range of attitudes and experiences regarding these forms of sexuality. I initially discuss the way a discourse of 'rights to sex' has been used in disabled peoples' campaigns for sexual citizenship to legitimatise the practices of commercial and non-commercial facilitated sex. Regarding commercial sex, I look at the motivations of disabled participants who purchase sex – all men – and locate them in dominant constructions of disability and masculinity. I also explore the complex power relationships in commercial sex work exchanges. Following this I look at participants' experiences of non-commercial facilitated sex, focusing predominantly on the integral role of the personal assistant (PA) within commercial sex purchases and the highly contentious practice of assisted masturbation. I conclude that these practices are problematically embedded within conventional gendered ideologies of power, heteronormativity, and masculinity, which not only serve to define, exclude and marginalise the sexual desires of disabled women, but reaffirm and maintain discourses of heteronormative sexuality.

Chapter 8: Conclusions

Through this concluding chapter, I initially draw together the main findings presented within and across different chapters in a brief summary of key findings. This summary not only acts as a road map for the reader, setting the scene before findings are explicated in greater detail throughout the remainder of the chapter, but more importantly shows the ways in which my key findings provide answers to my research questions. I then move on to locate these key findings in both the wider contexts of disability, sexuality and gender, and existing theoretical and empirical research and knowledge of disabled sexualities. In doing so, I show where my research and its findings make a contribution to knowledge.

Conclusion

In sum, this chapter has contextualised my research and outlined its specific areas of inquiry, and has provided a comprehensive overview of what will follow in this thesis. I have provided a rationale for why my research focus is upon this specific area of disabled peoples' lives and have set this in the multiple contexts of disabled peoples' social and political (activist) histories, disability scholarship, and popular culture. In addition, I have discussed the ableist discourses which desexualise and Other disabled people and have shown how these inform my specific areas of inquiry and build into to my research questions. Finally, I have detailed the contents, findings and conclusions of each chapter that follows.

Chapter 2: Theorising Disabled Sexuality: Constraints and Possibilities

Introduction

My research is based on a theoretical stance typical within emerging critical disability studies, incorporating a myriad of critical social theories such as feminism, interactionism, phenomenology, post-structuralism, queer, postmodern and psychoanalytic approaches to disability, gender, sexuality, identity, embodiment and subjectivity. This is because 'the global experience of disabled people is too complex to be rendered within one unitary model or set of ideas' (Shakespeare and Corker 2002: 15). As Shakespeare and Watson (2001: 19) state, 'a modernist theory of disability—seeking to provide an overarching meta-analysis covering all dimensions of every disabled person's experience—is not a useful or attainable concept'. Rather, critical disability studies form an emerging transdisciplinary space which 'connects the aspirations and ambitions of disabled people with transformative agendas of class, feminist, queer and postcolonial studies' (Goodley 2010: 174). They are, according to Goodley (2010: 157), spaces where 'impairment and disability are interrogated as phenomena acted at the levels of psyche, culture and society'.

This chapter provides a theoretical background to my empirical investigation, and asks more questions than it answers. I offer a critical overview of existing bodies of literature in order to make clear the terrain to which my research and its findings may contribute. The chapter is divided into two halves. The first concentrates on the problems and possibilities in theorising dis/ability. I outline the conceptualisations of disability and impairment that underpin my theoretical approach. I discuss first the ways in which the social model of disability is distinctly inadequate to explore disabled sexualities, and, following this, outline my more critical conceptualisation

of disablement. Next, through the need to fully theorise impairment as a social and cultural construct, I look at critical approaches to impairment and the impaired body which radically redefine it from an individual pathology to a body that 'can envelop and expand in exciting ways' (Goodley 2010: 158). In the second half of the chapter I turn the focus to writings on sexuality and consider the application of biological, post-structuralist, interactionist, and queer perspectives to disabled sexualities and examine how these different lenses, and their often-conflicting viewpoints, support my specific areas of inquiry. The chapter concludes by questioning whether critical social theories as currently constructed can adequately theorise the lived and embodied realities of disabled peoples' sexual and intimate lives.

Conceptualising Disability: Taking a Critical Look

Critical disability studies constitute a burgeoning area of critical social theories of disability and impairment (Erevelles 2005; Pothier and Devlin 2006; Shildrick 2007a) which enable the deconstruction of binary conceptualisations of disability and sexuality (Corker 1998, 1999), and further develop theories of embodiment, intersectionality, and identity. It has been questioned whether a more *critical* disability studies constitutes a 'radical paradigm shift or simply signifies a maturing of the discipline' (Meekosha and Shuttleworth 2009: 48). Either way, Meekosha and Shuttleworth (2009: 49) state that critical disability studies have 'accomplished a social, political, and intellectual re-evaluation of explanatory paradigms used to understand the lived experience of disabled people and potential ways forward for social, political and economic change'. They suggest,

'Use of CDS signifies an implicit understanding that the terms of

> engagement in disability studies have changed; that the struggle for social justice and diversity continues but on another plane of development – one that is not simply social, economic and political, but also psychological, cultural, discursive and carnal' (Meekosha and Shuttleworth 2009: 50).

Thus, critical disability studies substantially build upon earlier structuralist and experiential perspectives of disability (discussed later) to facilitate a radical redefinition of impairment and the impaired sexual body and interrogate the boundaries of normative sexuality. Using a critical disability studies approach offers a comprehensive 'theoretical toolkit' through which I will explore disabled peoples' experiences of sexual opportunities, identities, and intimate relationships. I begin this section by detailing the history of the social theory that gave birth to a more critical approach within disability studies, namely the 'strong social model' (Shakespeare and Watson 2001), and I outline the problems with using this model as a theoretical underpinning for my explorations. Next, I outline my conceptualisation of disablement, which is influenced by critical disability studies' contestations of 'dis/ableism' (Goodley 2010: 157). Following this, I look at the importance of conceptualising the lived experiences of impairment alongside disablement - the history of which, I suggest, is located in disabled feminists' critiques and crucial developments of 'malestream' structural disability theory - in order to understand how disabled people manage and negotiate their sexual lives and the psycho-emotional consequences of sexual oppression.

A Social Model of Disabled Sexuality?

The social model of disability (Oliver 1990) was born out the Union of the Physically Impaired Against Segregation (UPIAS), an early founding organisation of the British disability movement that radically shifted the meaning of 'disability' from the bodies of individuals to a product of the social world. The social model offers a predominantly Marxist and materialist-orientated approach to disability, laying 'the blame for disabled peoples' oppression clearly at the feet of economic relations in capitalistic society' (Meekosha and Shuttleworth 2009: 55). Within the social model, 'impairment' as the bodily bio-physiological condition of disability is determinedly marginalised in favour of a focus on 'disability' as a complex set of social relations that structure the experience of impairment. In this sense, the social model mirrors early (mainstream) feminist movements that distinguished between sex (as a 'natural' entity) and gender (the cultural construction of one's sex) (Rubin 1975). Such revolutionary redefinitions were rooted firmly within disabled peoples' self-organisation and mobilisation of independence and civil rights movements in Britain (Campbell and Oliver 1996; Barton and Oliver 1997). This purposeful redirection of focus towards exclusory social environments, which consisted of 'social and environmental barriers such as inaccessible buildings and transport, discriminatory attitudes and negative cultural stereotypes' (Barnes and Mercer 2003: 1), was intended to disassociate disabled people from medico-scientific models of disablement which 'situate disability exclusively in individual bodies and strives to cure them by particular treatment, isolating the patient as diseased or defective' (Siebers 2001: 738). This was disabled peoples' and movements' radical rejection of, and resistance to, their medicalised and pathologised existence. As Crow (1996: 207)

states, the introduction of the social model enabled a ‘vision of ourselves free from the constraints of disability (oppression) and provided a commitment for our social change - I don’t think it’s an exaggeration to say the social model has saved lives’.

The consequence of this ‘strong social model’ (Shakespeare and Watson 2001), with its unrelenting focus on civil rights and structural disablism, was that it simultaneously omitted equal political focus towards the private and intimate lives of disabled people. This omission was felt strongly within disability rights movements, although it was seldom publically acknowledged; as activist Anne Finger (1992: 02) stated in an early edition of the New Internationalist,

> ‘Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction.’

Thus, this marginalisation of sexual politics in favour of a focus on ‘survival level issues’ (Waxman-Fiduccia 2000: 168), Shakespeare (1999: 54) argues, has been at the expense of the more ‘personal and individual dimensions of oppression’ such as experience of impairment, sexuality and identity. The disinclination of rights movements and Disability Studies to attend to matters of sexuality and relationships, something Shildrick (2007: 226) calls the ‘self-censorship of the disability movement itself’, can be attributed to early social model proponents (Oliver 1990; Hunt 1981; Finkelstein 1980) who, in their eagerness to see society and the state, rather than disabled people, as the problem, wrote both the material body and subjective experiences out of their theorisations. This silence, Shakespeare (1996)

argues, served only to reproduce society's attitudes and contribute to disabled peoples' lack of sexual culture (Siebers 2008). According to Shakespeare (2000: 159), the reluctance to discuss sexuality was primarily about prioritisation, but was also because the movement in Britain at that time 'consciously tapped into the tradition of labour movement organizing, and adopted the paradigms of trades unionism and socialism, rather than the paradigms of consciousness raising and feminism'. In addition, at that time the 'Movement' was predominantly led by disabled men (Morris 1991) who ratified hard-line direct action, or 'macho politics' (Shakespeare 2000: 160) rather than a focus on more subjective or 'domestic' issues.

Because of such significant omissions, the social model of disability has been subjected to a substantial amount of critique and debate (Shakespeare et al 1996; Light 2000; Gabel and Peters 2004; Shakespeare and Watson 2001, 2002; Meekosha 1998; Crow 1996; Wendell 1996; Thomas 1999; Lonsdale 1990; Keith 1990; Morris 1991; 1993; Begum 1992; Hughes and Paterson 1997; Rembis 2010; Shakespeare 2006). Wide-ranging critiques, from feminist, critical realist, post-structural and postmodern theorists have challenged the social model on various grounds: its rigidity and anti-experiential nature (Corker and Thomas 2002); its masculinist and outdated principles (Crow 1996); its overlooking of the psycho-emotional consequences of disablement (Thomas 1999); its disembodied conceptualisation of disablement (Shakespeare and Watson 2001); its 'somatophobia' (Williams 1999); its 'inability to recognise sexual agency' (Gabel and Peters (2004: 594), and the notion that it has 'resulted in the policing of disabled people's experiences' (Thomas and Corker 2002: 629).

Such critiques have been articulated through disabled feminists talking openly

about their own bodies and experiences of impairment (see Crow 1996; Wendell 1996; Thomas 1999; Lonsdale 1990). Doing so has echoed the 'deconstruction of the public/private divide' (Sherry 2004: 776) advocated by feminist theorists. However, while this deconstruction of public and private realms emerged out of second wave feminism, it was disabled feminists' own engagement with this notion which instigated important changes, rather than via support from their non-disabled sisters whose 'narrow notions of womanhood' (Wilkerson 2002: 39) have largely excluded and overlooked the experiences of disabled women through what Sandoval (1991) labels 'hegemonic feminism' (Garland-Thompson 2002; Lonsdale 1990; Schriempft 2001; Thomas 1999; Wendell 1996; Keith 1990; Morris 1991, 1993, 1996; Begum 1992; Fine and Asch 1988). For example, Morris (1996: 1) argues that 'disability is a women's issue – in that the majority of disabled people are women – yet the experiences of disabled women have been largely absent from feminism's concerns'. Feminist explorations of reproductive rights, motherhood, domestic violence, abuse, and caring have predominantly excluded the experiences of disabled women from their analysis (Morris 1996). However, there have been noteworthy exceptions of non-disabled feminists interrogating their own inherent ableism (see Rohrer 2005; Lloyd 2001). However, this critique can be extended to much of social theory, since, as Davis (1999: 500) argues, the 'majority of academics do not consider disability to be part of their social conscience'.

As well as instigating important changes to recognise impairment within disability modelling, disabled feminists of this period made significant strides in locating gender within analyses of disability; a distinctly under-theorised dimension in disabled peoples' lives. Locating gender was important for variegated reasons: to challenge the degendered identities of disabled people (see Shakespeare 1997); to

recognise that ‘disabled women are in a relatively more disadvantaged position than disabled men’ (Thomas 2006: 178), and to establish that ‘the social forces and processes that construct and give shape to both gender and disability are closely intermeshed’ (Thomas 2006: 178). Early scholarship of disabled feminists aimed to define gender and disability experiences as constituting multiple oppressions (see Fine and Asch 1985; Deegan 1995; see Begum 1992). However, disabled feminist Morris (1998: 5) says of such developments: ‘I feel burdened by disadvantage and I feel a victim - such writings do not empower me’. Additionally, conceptualising disability and gender in this way ‘misses the social relational connections between them and the particular ways in which different configurations of disability and gender affect individual and group experiences’ (Traustadóttir 2006: 82). Moreover, it has previously been argued, in what Shakespeare (1999: 57) calls ‘the traditional account’, that cultural constructions of disability conflict more with dominant constructions of masculinities than femininities (see Murphy 1990; Connell1995); thus ‘femininity and disability reinforce each other, masculinity and disability conflict with each other’ (Shakespeare 1999: 57). However, it is now appreciated that the intersections of disability and gender, and other social identities such as sexuality and race, are far more complex (Shakespeare 1999) and thus that ‘disability affects the gendering process in many ways’ (Gerschick 2000: 1265). For example, Gerschick (2000: 1265) states that ‘all people do not experience the same degree and type of gender socialisation and expectation’; rather, the type, origin, effects, ‘visibility’ and trajectory of impairment and other social identities can mediate experiences of gender and impact upon the ability to enact socially and culturally ‘appropriate’ gender identities. However, disabled men still hold more social and economic power than disabled women; for example, ‘disabled women are more

likely to be poor than disabled men; are less likely to have access to rehabilitation and employment; are more likely to experience public space as threatening; and are more likely to live in the parental home and experience sexual abuse' (Goodley 2010: 35). Thus, it is, then, crucial to include the gendered dimensions of disability and impairment in my theorisations, particularly because gender and sexuality are entwined (Jackson 1999).

Returning to the social model, disabled feminists (and others), then, called for 'a renewed social model of disability' (Crow 1996: 218). Important within this struggle was the recognition of the differences between impairment and the embodiment of other oppressed groups, and the acknowledgement of impairment as a potentially negative bodily state; as Crow (1996: 209, original emphasis) states, 'sexuality, sex, and skin colour are neutral facts. In contrast, impairment means our experiences of our bodies *can* be unpleasant or difficult'. Morris (1991) proposes that this means bringing the real (gendered) body back in to theories of disability, both reflecting and contributing to the trend within other areas of sociology to 'bring the body back' (see Shilling 2003; Leder 1990; Frank 1995) (from which, paradoxically, the impaired body has largely been omitted) and acknowledging that the impaired body 'experiences real pain, nausea, fatigue and weakness' (Thomas 2002: 69).

These developments, of what Shakespeare and Watson (1997) call the 'strong' social model, which include subjectivity, embodiment and impairment within their theorisations, not only permit a better focus on personal lived experiences and intimate issues such as sexuality and intimate relationships, but enable an analytical focus on the intersectionalities of disability with other social identity categories, currently missing from much disability and sexuality research (Shuttleworth 2010;

see also Kanguade 2010; Hughes and Paterson 1997; Shakespeare et al 1996). This is because of its focus on subjectivity and thus its rejection of disabled people as a homogenous group; for example, as Goodley (2010: 33) states, 'a body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualized and classed'. Instead, developments of the social model avow an appreciation of the differences *between* disabled people (Thomas 2002), and thus enable inclusion of their multiple social identities (see Vernon 1999). This is with particular regard to the intersectionality of gender and disability, something many disabled feminists identify as a serious omission from the social model (e.g. Thomas 2002; Baron 1997; Begum 1992; Vernon 1996) and which consequentially has been overlooked in different research spaces. For example, disabled men's experiences of masculine subjectivities and identities remains under-theorised (Shakespeare et al 1996; Gerschick and Miller 1995; Vernon 1999) (largely because disabled feminists have theorized the lives of disabled women), and disabled women's issues (sexuality, motherhood, reproduction, imagery, relationships) have been overlooked more generally within the 'malestream' of disability theory and political life (Deegan and Brooks 1985).

Therefore, inclusion of disabled peoples' lived and embodied experiences is a crucial development within disability scholarship but it remains politically contentious 'since it tugs - somewhat disconcertingly - at the key conceptual distinction which was at the heart of the transformation of disability discourse from medical problem to emancipatory politics' (Hughes and Paterson 1997: 326). Such theoretical developments have, as Goodley (2010: 28) identifies, 'sparked outrage' from male architects of the social model and have been derided by them as 'sentimental biography' (Barnes 1998 in Goodley 2010: 28). Oliver (1996b: 52) has

also criticized these intellectual developments of the social model, claiming that they 'stretch the social model further than it is intended to go'. Furthermore, it has been suggested by others (see Light 2000; Sheldon et al 2007) that, as well as critiquing the social model, disability theorists should propose some meaningful alternatives. Critiques from post-structuralist disabled feminist Marian Corker (2002: 23) suggest that the inclusion of lived experiences of impairment in theorisations of disablement can mean that 'impairment is often conflated with personal experience and thus remains firmly located at the level of the individual'; furthermore, she argues that impairment is shrouded in negativity thus dampening the potentially extraordinary, productive and pleasurable nature of impairment which more recent critical approaches (discussed later) now emphasise. Other critiques centre on the notion that merely describing impairment and its bodily effects is to leave 'impairment' unproblematised, treating it only as 'biological' reality, and 'an objective, transhistorical and transcultural entity' (Tremain 2002: 34; see also Shakespeare and Watson 1995; Hughes and Paterson 1997; Corker 1999), an 'untouched, unchallenged; a taken for-granted fixed corporeality' (Meekosha 1998: 175), rather than examining impairment as a 'relational, constructed, and negotiable construct' (Goodley and Tregaskis 2006: 638) which is historically and culturally located and produced.

A Critical Disability

More recent critiques of the social model focus on its inability to theorise particular aspects of sexual life. For example, Shildrick (2007: 228) argues that the social model has very 'little or nothing to say on the subject of sexuality and has no place for the question of desire in particular'. Similarly, Rembis (2010: 54-56)

suggests that social model explorations of disabled sexualities are limited because they 'remain wedded to dominant heteronormative and ableist notions of gender and sexuality', failing to 'move beyond the binary, beyond male/female, masculine/feminine, adult/child-like, independent/dependent, nondisabled/disabled, sexual/asexual, straight/gay' thus reinforcing the heterosexual matrix (Butler 1993) rather than initiating a 're-visioning of gender, sexuality, and disability'. Such a re-visioning on the scale that Rembis (2010) proposes can only be achieved, I argue, through turning attention away from disability and onto ableist hegemony (Campbell 2001, 2009; Davis 2002; Rose 2001). Goodley (2010: 157) argues that underlying all critical disability studies is a commitment to destabilising and 'contesting dis/ableism'. The two are inherently linked: 'in order to analyse disablism we need to be mindful of the complementary hegemony of ableism' (Goodley 2010: 157). Thus, while key developments of the social model - particularly the acknowledgment of impairment and inclusion of intersectionality - provide a more multi-faceted view of the disability experience and an embodied disabled subject (upon which I will draw in my own explorations), a critical conceptualisation of disability which is embedded in a critique of the wider ableist context offers far more scope to my investigations, as I will discuss below.

Critical disability studies provide the means through which to interrogate sexual normalcy and heteronormativity, as well as redefine disablement in the wider context of ableism. This critique is similar to queer theory in so far as it argues that the stability of the normative standard depends on the identification of and denigration of a binary; for example, heterosexual/homosexual. Within this chapter, I use Sherry's (2004: 770) definition of the term 'queer' as 'a range of sexual

identities and practices which do not conform to heteronormativity' and McRuer's (2002: 222) definition of 'queer theory' as 'a diverse array of projects that explore the construction and shifting contemporary meanings of sexuality'. Similarly, critical disability studies interrogate ableist institutions that which (re)produce the necessity and naturalness of the 'able' body and contribute to 'thanatopolitics', defined by Rose (2001) as the increasingly ableist-obsessed nature of everyday life. Through the construction of the disabled body, for example, theorists such as Lennard Davis (1995: 158) propose that hegemonic normalcy is upheld. Not only does 'the notion of normalcy makes the idea of disability as well as the ideas of race, class, and gender possible', the construction of Othered bodies legitimates and provides authority to notions of normalcy. Other theorists (see Michalko 2002) have highlighted the fragility of the non-impaired body by using the term TAB, or Temporarily Able Bodied, as a means through which to destabilise the apparent boundaries of dis/abled and normal/other. McRuer (2006: 2) puts forward the idea of 'compulsory able-bodiedness' based upon feminist/queer notions of 'compulsory heterosexuality' (Rich 1978). He argues that

> 'the system of compulsory able-bodiedness which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: that, in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness and vice versa'.

Thus an 'able' body is not a queer one, and a queered body is one that is 'disabled'. In addition, McRuer (2006: 9) contends that in much the same way that Butler (1990) suggests the very fixity of heterosexual hegemony is maintained through

repetitive performances of heterosexuality and (hetero)normative genders, this is similar to the extent to which 'institutions in our culture are showcases for able-bodied performance'. He maintains:

> 'The culture asking such questions assumes in advance that we all agree: able-bodied identities, able-bodied perspectives are preferable and that we all, collectively, are aiming for. A system of compulsory able-bodiedness repeatedly demands that people with disabilities embody for others an affirmative answer to the unspoken question, "Yes, but in the end, wouldn't you rather be more like me?"' (McRuer 2006: 9)

More importantly, he suggests, is that despite repetition of the heterosexual and able-bodied identity, both are doomed to fail: 'they are incomprehensible in that each is an identity that is simultaneously the ground on which all identities supposedly rest and an impressive achievement that is always deferred and thus never really guaranteed' (McRuer 2006: 9). Thus McRuer (2006: 10) proposes - based upon what he labels "ability trouble" (extended from Butler's concept of "gender trouble") - that, despite its compulsory nature, able-bodiedness is an impossibility, therefore making everyone 'virtually disabled' (Goodley 2010: 41).

Theorising Impairment and the Lived Experience

I consider that disabled peoples' experiences of sexual opportunities, identities, and intimate relationships, and their ability to exercise sexual agency and manage and negotiate these aspects of their intimate lives is as much shaped by the lived experience of impairment as through ableist constructions of disabled sexualities; thus it is imperative to fully theorise impairment. Furthermore, the danger of not

sufficiently theorising impairment alongside disability in general terms, Marks (1999: 611) argues, means that 'a theoretical vacuum is left, which is filled by those who adopt an individualistic and decontextualised perspective'. Paterson and Hughes (1999: 597-598) suggest that disability studies' 'unembodied' conceptualisations have 'failed to address adequately the fundamental issue of bodily agency'; they suggest that the 'Cartesianised subject it [disability studies] produces does not provide for an emancipatory politics of identity'. Thomas (2002: 20) argues that not only does the *experience* of impairment need to be considered, but 'impairment effects', which she defines as 'the direct effects of impairment which differentiate bodily functioning from that which is socially construed to be normal or usual'. The rationale for considering 'impairment effects' is that 'in our society, these impairment effects generally, but not always, become the medium for the social relational enactment of disability: social exclusionary and discriminatory practices' (Thomas 2002: 20). Thus, it is the social interaction of disability and 'impairment effects', together, which form the lived experience of disability. There is, therefore, a need for a sociology of impairment alongside disablement to ensure the 'realignment of the impairment/disability distinction' at its core (Paterson and Hughes 1999: 598).

Paterson and Hughes (1999: 329) suggest that in order to move past social model perspectives which, they argue, problematically construct the body as 'devoid of meaning, a dysfunctional, anatomical, corporeal mass obdurate in its resignification and phenomenologically dead, without intentionality or agency', phenomenology is the means through which to reconceptualise the impaired body as entwined with culture, the social, and embodiment. Merleau-Ponty's (1962) phenomenology proposes that our bodies are the means through which the outside

world is experienced and helps 'us to understand the body/self as an imbricated whole, which rests upon, amongst other aspects, corporeal capacities and intentionality' (Davy 2010: 181). Paterson and Hughes (1999: 609) argue that impairment is formed as experience:

> 'oppression is not simply produced by structural barriers, it is manifest in corporeal and intercorporeal norms and conventions, and can be read in and through the ways in which 'everyday encounters' can go astray. From this perspective we can begin to analyse how impairment is produced as experience'

Davy (2010) argues that phenomenology, because of its focus on the corporeality of knowledge and experience, has been overlooked by disability scholars who are cautious of its application to disability and impairment for fear of returning to individualizing discourses. However, she argues that 'disability scholars seem to be equating bodily capacities with those of a universalized normative (masculine) standard, which is not necessarily the case in phenomenological interpretations' which can 'decentralise the universalized non-disabled body and draw attention to gender relations and sexual difference, illustrating that it can be useful for understanding bodies from other than what is assumed' (Davy 2010: 181).

However, Shildrick (2009: 32) argues that mainstream phenomenology 'implies that those who do not seemingly intermesh with the world as embodied subjects experience bodily discontinuities as disruptions or blockages to their own self-possession'. Thus, she suggests, the body 'becomes an unwelcome presence which signals limitation and vulnerability' '(Shildrick 2009: 32), therefore becoming a body that is treated only as a problem and is repathologised. Thus, while

phenomenology provides a lens through which impairment and the body (or experiencing of the body) becomes central to lived experiences of sexual life, my inquiry into the strategies disabled people may employ in the making of their sexual self lies principally with the potentiality and possibilities of impairment, making phenomenological interpretations of the body comparatively insufficient.

Rather than impairment as an 'unwelcome presence' (Shildrick 2009: 32), I consider impairment as the means through which pleasure and desire *can be* embodied and experienced in an affirmative way. For example, the ways in which disabled people can 'adapt their impairments using different positions and various sexual aids to facilitate sexual fulfilment' (Shuttleworth 2010: 3) and potentially 'open up new (sexual) horizons' (Shildrick 2009: 36) that 'exceed the socio-cultural normativities of sexuality in a productive way' (Shildrick 2009: 13). Thus critical disability studies' celebration of the perverse, the spectacle, and the non-normative not only rejects dominant medically-imposed notions of impairment as a deficit, but, instead, 'impairment' becomes bodily difference, revision, and transgression, a space whereby non-normative embodiment is now revered, having shed itself of prevailing ableist discourse which define it as lacking, inferior and Other.

The 'new mode of representation' Siebers (2008: 54) of the impaired sexual body is realised through disabled queer political activism, notably through slogans which exemplify the productive realities of impairment within sex: "trached dykes eat pussy all night without coming up for air" (O'Toole 2000). Other theorists such as Smith and Sparkes (2002, 2003) have redefined bodies after injury as bodies that are capable of being revised and rewired; queer theorist Wilkerson (2002: 51) proposes that impaired bodies can experience polymorphous pleasures, and Goodley

(2010: 158) suggests that impaired 'bodies can envelop and expand in exciting ways'. Furthermore, the work of feminist postmodernists whose work examines the role of technology in the making of the body enhances the *possibilities* of the impaired body, for example Haraway's (1991) cyborg metaphor. Harraway (1991: 178) herself delineates a possible cyborg as 'perhaps paraplegics and other severely handicapped (sic) people can (and sometimes do) have the most intense experiences of complex hybridisation with other communication devices'. While it is important not to forget the largely oppressive historical influence of technology upon the impaired body and disabled identity, emerging technologies enable an exciting redefinition of conventional bodily boundaries and body politics. As Meekosha and Shuttleworth (2009: 60) suggest,

> 'the possibility that we could reconstitute our bodies, both as mechanical and organic, with the aid of prostheses and other mechanical devices means that we can embrace new technologies with positive identities rather than feeling victims of inadequate functioning'.

Such radical redefinitions of the body are powerfully transformative and can be fruitfully applied to (disabled) non-normative sexualities. However, a notable critique of postmodernist constructions of the body centre on how such radical theorisations of impairment often fail to give enough consideration to the social and institutional conditions in which (most) disabled people live and the dis/ableist systems through which they are produced. Particularly, the ways in which such perspectives remain largely out of reach within the self-definition of the majority of disabled people outside of the academy and radical politics. Therefore, throughout my research I question how far participants are able to explore these possibilities. I

ask how realistic and accessible the notion that impairment has the potential to promote sexual creativity and open sexual opportunities and possibilities (rather than foreclose them) is for disabled people; I also consider the ways in which this is mediated and/or negotiated in the context of the embodied realities of impairment.

Another area of my inquiry focuses upon the psycho-emotional consequences of owning and occupying a sexual body and identity marked by oppressive ableist constructions of disabled sexualities, and the possible psycho-emotional consequences of participants' own strategies towards mediating these constructions. I have further interest in the inter-relationship of gender with this form of disablism; as Thomas (2006: 182) proposes, psycho-emotional disablism is a form of disablism that works with and upon gendered realities; it operates along psychological and emotional pathways and frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden'. Central to this, then, is participants' feelings and psychic responses to living in disabling cultures: the psycho-emotional consequences of sexual oppression (and disablism), their internalised oppression and its meaning, and how all these impact upon the sexual self and shape the ways in which ableist sexual stereotypes can be managed, negotiated and resisted. As Marks (1999: 615) states 'it is important to examine not just the relationship which people have with others, but also the relationship they have with themselves'. Goodley (2011: 716) suggests that

> 'The psyche can be understood as a cultural artefact of contemporary society that individualises social problems. Individual, medical, bio-psychological, traditional, charity and moral models of disability locate social problems in the heads and bodies – the psyches – of (disabled)

> people. This leads to the commonly held view that disabling society is not the problem: the disabled psyche is. In contrast, the psyche can be reconsidered as a complex tightened knot of the person and the social world, the self and other people, the individual and society. At the heart of this is the internalised experience of disablism: oppression is felt psychically, subjectively and emotionally but is always socially, cultural, politically and economically produced.'

Thus the disabled psyche (which is produced within an ableist cultural imaginary) is central to the lived experiences of sexual life, and plays an important role within the formation or reformation of a sexual identity in an ableist culture whereby it is restricted. Through her analysis of the 'dangerous discourses' of anxiety, desire and disability, Shildrick (2007: 221) draws attention to Western anxiety at the expression of erotic desire which 'cannot be subsumed unproblematically under the rubric of the normative body'; for example children's bodies, old bodies and disabled bodies. Thus, she suggests, the cultural imaginary closes down the possibilities of a sexual self for disabled people because the anomalously embodied disabled sexual subject represents the pinnacle of Western anxiety surrounding both the erotic and disablement. While the erotic, 'the coming together of any bodies and more specifically the intercorporeality of much sexuality', already causes anxiety within us all because of the 'loss of self-definition' such sexual relations entail, then this anxiety, Shildrick (2007: 226) argues, is at 'its most acute where the body of the other already breaches normative standards of embodiment'. For disabled people, this results in 'disqualification from discourses of sexuality but also raises the contested question of who is to count as a *sexual* subject' (Shildrick 2007: 221,

original emphasis). Thus in order to fully conceptualise the lived experience of sexual life for disabled people it is imperative to account for the role of the cultural imaginary in the creation of the disabled (sexual) psyche, particularly where sexual self esteem and worth are dependent upon normative sexuality and embodiment.

To sum up this section, then, the conceptualisations of both disability and impairment that underpin my explorations move beyond social model conceptualisations and towards more critical theorisations, which enable a clearer focus upon embodiment, intersectionality, and identity which are central to sexual life. I have suggested that the social model, for a panoply of reasons, is largely inadequate when researching disabled sexualities because, by very design, it only stretches focus to the material, the outside and the public, and, as its history has shown, offers little in terms of exploring the private, gendered, embodied and intimate spaces of disabled peoples' lives (Keith 1990; Morris 1991; Shakespeare et al 1996; Shakespeare and Watson 2001) and the intersections of their identities (Shakespeare et al 1996; Shuttleworth 2010; see also Kanguade 2010; Hughes and Paterson 1997). While the social model has previously been used as a theoretical foundation within empirical studies of disabled sexualities, as outlined in chapter one (see Shakespeare et al 1996), it has seldom captured more than the social barriers to sexuality for disabled people, leaving desire (Shildrick 2007), pleasure, and the means through which people with impaired bodies appropriate these, distinctly unattended (Shuttleworth 2010). Alongside this, it has failed to deconstruct the binaries that dominate disability studies and has problematically affirmed and maintained the dominant ableist notions of heteronormative sexuality and gender that oppress disabled people (Rembis 2010). Therefore, as I have illustrated, engaging

with critical theories offers a far more relevant means through which I can explore intimacy, embodiment and subjectivity, and provides a necessary radical redefinition and inversion of disability and impairment, opening up the possibilities of disabled sexualities at the same time as challenging the restrictive boundaries of sexual normativity. However, while I advocate later critical approaches to disability and impairment because of the very (sexual) possibilities they open up, I treat the social model and critical theory as additive, seeking to remain equally mindful of the structural and economic constraints upon opportunities for sexual fulfilment within the lived experiences of sexual life for disabled people.

Theorising Sexuality

As with contested notions of disability and lived experiences of impairment, I draw my conceptualisation of 'sexuality' from a range of theoretical frameworks. A broad constructionist approach largely underpins the conceptualisation of sexuality as socially constructed and regulated, and it was my initial engagement with post-structuralist and interactionist perspectives which enabled much of this thinking. Early constructionism (e.g. Gagnon and Simon 1973), which 'had its roots in phenomenological and interactionist sociology' (Jackson and Scott 2010: 5), redefined the scholarly field of sexualities from the 1960s onwards, enabling a rejection of essentialist 'pre-social' notions of sexual needs and moving towards a redefinition of sexuality as socially produced (Jackson and Scott 2010). The essentialist notion of sexuality as only a biological entity, Jackson (1999) argues, denies human agency and autonomy, and is an 'ethological fallacy' (Gagnon and Simon 1973: 3) that pays no heed to humans as 'complex, arbitrary and changeable creatures' (Weeks 1986: 46). Weeks argues that humans,

> ‘manipulate language to reshape perceptions of the world and of sex, defy the apparent logic of external appearances, blur the edges between masculinity and femininity, create differences that transcend the differences of gender and construct boundaries that have little logic in Nature’.

In the first part of this section I outline the inherent dangers of utilising biological perspectives of sexuality in research on disabled peoples’ sexual lives, detailing the reasons why an essentialist approach needs to be discarded. I then draw upon forms of constructionism with specific reference to disabled sexualities, considering their contributions towards theorising disabled peoples’ sexual opportunities, identities, and intimate relationships. It is here that I return once again to critical social theories, looking at the ways in which queer theory, psychoanalytic and critical disability studies serve to conceptualise the lived experiences of sexual life for disabled people through contesting the hegemony of ableism, sexual normalcy and heteronormativity.

Rejecting the Biological

Biological conceptualisations of sexuality are primarily based upon the assumption that, as stated by Weeks (1986: 13), ‘our sexuality is the most spontaneously natural thing about us’. Thus sexuality is ‘innate, instinctual, animalistic, and physiological law’ (Weeks 1985: 82). This perspective on sexuality is central to by the discipline of Sexology, which focuses on the study and classification of sexual behaviours, identities and relations' (Bland and Doan 1998: 1). To provide a concise overview, post-Darwinian scientific paradigms of sex (e.g. Krafft-Ebing 1899; Ellis 1927) studied sexual pathologies, thereby establishing the

sexual norm by contrast to its deviations. Later works from the early twentieth century onwards took an empiricist approach and made sex an 'object of study' (Hawkes 1996: 56). For example, the works of Kinsey (1948, 1953), Chesser (1950), Masters and Johnson (1966) and others sought to quantify, measure, define and chart key stages of human sexual experiences.

These biological approaches to sexuality arguably uphold and maintain a heteronormative order based upon traditional heterosexual gender ideals from which disabled people are more explicitly excluded than non-disabled people (see Thomas 1999; Wendell 1996; Morris 1996). For example, the male is situated as dominant, animalistic, and powerful and its reductionist phallocentrism places significant emphasis on stamina, performance, and bodily function, which can serve to castrate and emasculate disabled men (Drench 1992; Shakespeare 1996; Murphy 1990). Simultaneously, biologicalist approaches put reproductive function at the heart of sexuality. Jackson (1999: 05) states that for biological determinists 'sexuality is both definable and explicable in terms of a reproductive imperative'. But in so far as, as Tepper (2000: 285) argues, 'reproduction is solely the province of the fittest', the links between reproduction and sexuality exclude people with disabilities. Similarly, Waxman-Fiduccia (2000: 169) states that 'sexual rights have always and only been awarded to those who are proclaimed to deliver quality offspring'; thus, she argues, biomedicine seeks to control and regulate the fertility of the dangerous disabled female. By regulating female sexuality and reproduction as suggested by Waxman-Fiduccia (2000) and others (e.g. Anderson and Kitchen 2000; Kent 2002; Lee and Heykyung 2005), the female body is essentially denied reproductive freedom (Waxman and Finger 1991).

Furthermore, the physiological norms established by sexual medicine also served to Other disabled sexualities. For example, Masters and Johnson's (1966) conceptualisation of the sexual response cycle quantified what they defined as the key physiological aspects of sexuality, such as attraction, arousal and orgasm, which established a 'physiological norm' and instigated a discourse of pleasure within sex (particularly for women) under the guise of 'liberation' (Tiefer 2001). However, this norm was firmly based on the ability to 'achieve' orgasm (Tepper 2002), defining different experiences as dysfunctional, inadequate, and in need of treatment (Bullough 1994; Hawkes 1996). The assumption of conventional functionality of the body, then – something Tepper (2000: 288) calls 'a genitally focused and performance orientated conception of sexuality' – necessarily devalues the potentialities of impairment for sexual pleasure, desire and behaviour. In addition, such a focus on body function means that sexuality becomes the province of doctors and other related professionals who become 'gate-keepers' to disabled peoples' sexual lives (Shakespeare et al 1996). Thus it places the fate of disabled peoples' sexual selves at the mercy of a paradigm that devalues the possibilities of their bodies (Hahn 1981; Milligan and Naudfeldt 2001; Tepper 1999, 2000; Anderson and Kitchen 2000) and serves to further medicalise the lives and bodies of disabled people and place disability (and sexual 'failure') back onto the individual. However, whilst the policing of disabled peoples' sexual and reproductive lives by medical professionals has been more explicit in the past, there are more progressive movements emerging within particular areas of medicine where certain health professionals (e.g. nurses) are incorporating social model values into their work (Brichner 2000) and that there is, particularly in the current age of genetic intervention, a far more complicated relationship between medicine and disabled

people which as much involves interdependencies as it does objectification. However, medicine's propagation of the physiological norm of the 'able' sexual body, Shakespeare et al (1996: 66) argue, invites a biomedical gaze which reinforces and advocates the need for sexual treatments and therapies, and serves to contribute to the medical voyeurism of disabled people as 'subjects and fetishized objects' (Shakespeare et al 1996: 03; see also Solvang 2007; Waxman Fiduccia 1999).

Socially Constructed Sexualities and Sexual Bodies

A broadly social constructionist, rather than biological, approach, which defines social reality as 'shaped through a system of social, cultural and interpersonal processes' (Villanueva 1997: 18), is the only suitable means through which I *begin* thinking about disabled peoples' experiences of sexual and intimate life. However, social constructionist approaches do not offer the 'end point'. Shildrick (2007) argues that social constructionist perspectives overlook embodiment, corporeality and the psychic. This is distinctly problematic when, for many disabled people, the very embodiment of impairment constitutes a substantive part of the reality of their lived experience of disablement and thus is central to their sexual story. Here, I discuss the contributions of post-structuralism and forms of interactionism to the theoretical conceptualisation of sexuality underpinning my research.

Goodley (2010: 106) argues that post-structuralism's deconstruction of binaries 'privileges the other (e.g. black, woman, passion, irrational, disabled) and opens up the in-betweenness of binaries'. This, he suggests, potentially offers 'spaces for resistance – creating a new epidemic – a resignification of disability' (Goodley 2010: 106). Thus, deconstructing the discursive binary of dis/abled that

reinforces embedded constructions of normalcy (Overboe 2007a) enables us to 'ask how one has become empowered through comparison with, and denigration of, the other' (Goodley 2010: 105). Disability theorists have long utilised poststructuralism, particularly Foucauldian theory and the role of discourse, and have applied it to critically examine both disability and impairment (see Tremain 2002; Shildrick and Price 1996). However, this has been argued to blur the intersectionality of gender and disability because, as Thomas (2006: 184) states, 'post-structuralists face particular difficulties here, because their opposition to dualistic thinking in this case the men/women, masculine/feminine dualisms destabilizes the very project of examining gender differences'.

Foucault (1976: 136) proposes that power operates between and through bodies via mechanisms of self-discipline rather than through repressive powers in the form of physical forces extraneous to the body. Thus, for Foucault (1976: 136), the body is rendered 'docile', 'subjected, used, transformed, and improved'. However, although Foucault's docile body is problematically degendered (Jackson 1999; Ramazanoglu 1993; Smart 1992; Bartky 1990; Marshall and Katz 2002), and portrays 'disabled people as largely passive witnesses to discursive practices' (Barnes and Mercer 2003: 86; see also Thomas 2006), Foucauldian theory is simultaneously useful towards interrogating what constitutes impairment and its inherent naturalness (Tremain 2000). From a discursive point of view, as Tremain (2000: 296) suggests,

> '"the body" has no pre-given materiality, structure, or meaning prior to its articulation in discourse. Rather, the very articulation of "a (material) body" in discourse is a dimension of what materializes that "body" in the

first place'.

For example, Foucault's (1976: 140) notion of biopower, defined as 'an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations' is relevant to the ways in which the impaired body, as *naturalised* through discourse, has, in ways seen as legitimate, been observed, treated, and eradicated through contemporary and historic eugenicist efforts which surround impaired bodies and people (Morris 1991; Sobsey 1994; Waxman 1994; Tremain 2005a). Similarly, Goodley (2010: 114) argues that the impaired body is an 'educated, parented, observed, tested, measured, treated, psychologised entity', thus the impaired body itself is 'materialised through a multitude of disciplinary practices and institutional discourses'. Hughes and Patterson (1997: 332) argue that even the bodily experiences of the impaired body are discursive because the meaning of such bodily experiences is articulated through language, 'somatic sensations themselves are discursively constructed'.

However, as with the earlier debates about impairment (see previous section), the discursive body is heavily contested by certain critical realist corners of disability studies (see Shakespeare and Watson 1997; Wendell 1996), wherein caution is expressed. Critical realism defines the body as 'is a real entity, no matter what we call it or how we observe it. It also, like all other social and natural domains, has its own mind-independent generative structures and causal mechanisms' (Williams 1999: 806). If post-modern emphasis on discourse leads to considering impairment as *predominately* discursive – or, rather, that impairment doesn't exist extraneous to discursive construction – this may deny the body's materiality, the lived and embodied experience of which may include pain, exhaustion, and immobility. For

example, disability activist Wade's (1994: 88-89) assessment of the impaired body emphasises this position:

> 'To put it bluntly – because this is as blunt as it gets – we must have our arse cleaned after we shit and pee, or we have others' fingers inserted into our rectums to assist shitting. The blunt, crude realities... If we are ever to really be at home in the world and in ourselves, then we must say these things out loud. And we must say them with real language'.

Thus the primary concern is that, as Wendell (1996: 45) argues, 'in post-modern cultural theorising about the body, there is no recognition of the hard physical realities faced by disabled people'. Thus, in this sense, overlooking the role of such 'hard physical realities' (Wendell 1996: 45) of the impaired body offers little support to the notion that impairment (and its bodily effects) may play an integral role within disabled peoples' interpretations of their own gendered sexual bodies and identities, which may be problematic to my aim to not lose touch with disabled peoples' actual lived (rather than theorised) experiences. Thus while impairment is produced and materialised through discourse (Tremain 2000), postmodern discursive theory fails to give enough credence to the pragmatic gritty realities of impairment and, more importantly, the meanings of such realities to disabled people. There is therefore a tension between these respective approaches which I further explore elsewhere in this thesis. However, while it is imperative to recognise and acknowledge such theoretical tension, it is not to say that these differing perspectives cannot be applied (as I do with 'traditional' structural and critical theories of disability and impairment) in an additive manner within my explorations, or that they both propose totalising ideologies that cannot be viewed through a more nuanced lens. As Thomas (2001:

60) proposes, ‘perhaps the challenge in developing a non-reductionist materialist ontology of the body and of impairment is to try to overcome the dualisms that besets our thinking, especially essentialism/constructionist; biology/society; nature/culture’.

With specific regard to disabled sexualities, while a Foucauldian perspective of sexuality is implicitly in reference to the construction of male sexuality (Jackson 1999), it none-the-less opens up consideration of the ways in which sexualities are discursively constructed, maintained and regulated through discourse. Through his rejection of the ‘repressive hypothesis’ in the first volume of his *History of Sexuality*, Foucault (1976) positions sexuality as a discursive construct, suggesting that the apparent ‘repression’ of the sexual in Victorian society was underwritten by proliferation of and incitement to discourse, a ‘discursive explosion’, which paradoxically *produced* sexualities and served to construct sexuality. The knowledge of sexual behaviours was developed as a way for intimate lives and bodies to be surveilled. Thus, the act of defining and labelling sexualities is a central aspect of biopower. Foucauldian theory therefore enables a complex consideration of the role of discourse within disabled peoples’ sexual and intimate lives and indeed in the knowledge production on disability. Foucault located the regulation of sexuality in the multiple discursive formations of pedagogy, medicine, psychiatry, social welfare, and law. His primary concern was not *what* was spoken about sex or its public prohibition, but,

> ‘to account for the fact that it is spoken about, to discover who does the speaking, the positions and viewpoints from which they speak, the institutions which prompt people to speak about it and which store and

> distribute the things that are said. What is at issue [is] the way in which sex is put into discourse'. (Foucault 1976: 11)

Within the lives of many disabled people, it is ableist institutions which regulate and oppress the sexualities of disabled people. As Kafer (2003: 85) suggests, 'while the sexuality of disabled people may be denied in conversations, it is being denied loudly and repeatedly, not silently'. For example, biomedical discourse classifies the sexual and reproductive capabilities of impaired bodies as defunct and dangerous and the medical-management of impaired bodies ensures that disabled peoples' sexual selves are regulated according to the biomedical objective of eradicating impairment. Similarly, media discourses, which Dune and Shuttleworth (2009: 97) state have 'exerted significant influence in the way that people experience and express their sexuality', render the disabled body both invisible (apart from when it 'fits' dominant cultural narratives of disablement) and abject through its propagation and affirmation of unreachable Western beauty aesthetics. The impaired body and disabled identity is further objectified through cultural representations in classic literature and drama that link to sin, evilness, and failure (see Shearer 1980; Shakespeare 1994). Film narratives in the West routinely portray ableist sexual stereotypes whereby 'disabled people are asexual, undesirable, not sexually adventurous and have more important issues to worry about aside from sexuality' (Stevens 2010: 60). The inherent ableism of public health discourses results in little sexual health service provision for disabled populations (Shakespeare 1996; Anderson and Kitchen 2000), and sex and relationship curricula (where it is afforded to disabled people) serves to perpetuate the normative body and heteronormative sexuality (see chapter four). The institution of the family may also serve as a means

through which such discourses are reproduced, particularly as a result of inadequate support and education for parents of disabled children (Olsen and Clarke 2003). Thus, disabled sexualities are regulated, as Foucault would argue, through 'a multiplicity of discourses produced by a whole series of mechanisms operating in different institutions'.

To Foucault, power is 'the tangible but forceful reality of social existence and of all social relations' (Weeks 1986: 07). Thus rather than purely repressive, power is 'polymorphous' (Foucault 1976: 11), it is negotiable and interchangeable, and can take a variety of forms. Shuttleworth and Meekosha (2009: 57) argue that Foucault's perspective on power is of great value to critical disability studies because it 'performs a radical de-familiarisation of modern institutions and practices as caring and benevolent and reveals technologies and procedures that classify, normalise, manage, and control anomalous body-subjects'. They argue that it moves disability studies away from its 'juridical concept of power' to consider 'not only legitimate and overt forms of control, but also a micropolitics of power in which modern human beings are complicit with their subjection' (Meekosha and Shuttleworth 2009: 57). Similarly, Gabel and Peters (2004: 592) suggest that 'the circulation of power through social relations' can highlight forms of resistance. Thus a Foucauldian theorisation of power enables a complex understanding of not only the means through which disabled people can be potentially sexually agentic and strategic when negotiating a sexual self, but also the ways in which disabled people may (unknowingly) act as their own oppressors; for example, through what Shakespeare et al (1996: 40) call internalised oppression, the 'emotional and psychological barriers' that 'prevent disabled people from becoming fully

functioning human beings, with healthy sexual identities and active, life-enhancing sex lives'.

However, Foucault's undervaluation of certain forms of structural and political power could also be argued to be problematic when applied to disablement as 'a complex system of social restrictions imposed on people with impairments by a highly discriminatory society' (Barnes 1991: 1). The assumption that normalising and disciplinary powers are more controlling than political powers is to 'ignore important political transformations' (Weeks 1986: 9). Thus, overlooking the oppressive ableist and disablist social systems in which disabled people live offers little attention to the ways in which disabled sexualities (as a sexual category) will change over time alongside disabled peoples' political empowerment. While disabled sexualities – or any sexual categories – are produced and sustained through discourse, they are also forever subject to political power in the form of state regulation, sanction or prohibition. As proponents of sexual citizenship claim, sexual citizenship and civil citizenship are interlaced and mutually dependent (e.g. see Plummer 1995; Giddens 1992; Richardson 1998; Weeks 1998). For Wilkerson (2002: 33, 35), 'sexual agency is integral to political agency', and thus 'sexual democracy should be recognised as a key political struggle'. Thus, as Siebers (2008: 154) contests, if we are 'to liberate disabled sexuality and give to disabled people a sexual culture of their own, their status as sexual minority requires the protection of citizenship rights similar to those being claimed by other sexual minorities'. Moreover, Foucault's overlooking of patriarchal power in favour of a juridico-discursive model 'leaves us without the means of effectively analysing power over others and the production of systematic inequalities – including those of gender'

(Jackson and Scott 2010). Jackson and Scott (1997) state that discursive constructions which regulate sexuality in modern society – for example, (sexual) competence, being a sexual pleasure provider, desire, the naturalisation of sex, the need for sexual skill and introspection – are all gendered discourses. For example, sexual competence (the necessity/lack of being a 'skilled' lover/performer), they state, is 'highly gendered':

> 'Where women are seen as candidates for therapeutic intervention this is still largely seen as a problem 'in their heads', a mental 'block' to be overcome. The model is one of repression causing 'impaired desire' or 'orgasmic dysfunction' from which women need to be 'liberated'. Male 'dysfunctionality' is more likely to be located in the body, localised in the penis. However elaborate and varied the sexual practices recommended in modern sex manuals have become, the syntax of heterosexual sex has largely remained unaltered: increasingly elaborate foreplay still leads to coitus. However skilled a man might be with hands or tongue, if his penis isn't up to it, he has failed in his performance. (Jackson and Scott 1997: 563)

Thus, to position sexuality as discursively produced, but conceptualise discourse as gender-neutral is inherently problematic when theorising sexuality. Discursive constructionism, then, in a Foucauldian formation, doesn't offer much scope with which to explore a gendered dimension of disabled sexualities, the relative sexual power between disabled men and women, and thus risks reaffirming the widespread degendering of the disabled identity. Failing to acknowledge or appreciate gender as a locus of power means overlooking the complexities of the relationships between

constructions of gender, impairment and disability (see Shakespeare et al 1996).

Jackson and Scott (2010: 37) argue that a more efficient lens through which to explore 'the relationship between gender and sexuality' is a symbolic interactionist one, which has 'considerable potential for feminist analysis'. Additionally, while Foucauldian and other post-structuralist approaches to sexuality envision mass networks of disciplinary power as discursively constituting sexualities, they offer less focus upon the everyday interactions through which meaning is experienced. In contrast, symbolic interactionist perspectives draw attention to the very subjective experiences and individual meanings of sexual identity (see Weeks 1986) and reinstate the 'significant dimensions of sexual life that are missing from Foucauldian approaches: everyday interpersonal interaction, the meanings deployed within it and the agency and reflexivity it entails' (Jackson and Scott 2010: 36). For example, I suggest that disabled peoples' experiences of sexual opportunities, identities and encounters are not only produced or reproduced within discourse engendered from a variety of social institutions, but emanate within and through disabled peoples' interpersonal interactions with others; for example, with sexual partners, teachers, PAs, parents, friends, peers, carers, doctors, physiotherapists, and support staff, who can, knowingly and unknowingly, contribute to the shaping of disabled sexualities and sexual expression. As Jackson and Scott (1997: 97) suggest, the meaningful social reality of 'embodied sexual encounters' are constituted 'not only through discourse but also through the meaning-making emergent from, and negotiated within, situated everyday interaction'. Brickell (2006: 417) suggests that symbolic interactionism,

> ‘is used to explore how meanings are created, assembled, negotiated and modified by members of a society. It presumes meaning to be an emergent property of human interactions, not something intrinsic to an individual or a situation. Accordingly, we construct the meaning of our social world and our own lives through our interactions with other people, gathering together and negotiating meaning as we participate in social life. Our interpretations about what constitutes ‘reality’ are worked and reworked within multiple ‘interaction orders’: the domains of face-to-face interaction between people in given contexts, domains whose communications are governed by particular rules and conditions’.

Thus, focusing upon the microsociological and the ways in which ‘members of a society manipulate cultural resources – meanings and symbols – in order to construct a common world and their place in that world’ (Brickell 2006: 416) also facilitates a view of disabled people as architects, negotiators, and managers of their sexual and gendered selves, and the meanings attached to such experiences (their ‘reality’). Plummer (1975: 13) states that interactionism focuses upon ‘emergence and negotiation – the processes by which social action (in groups, organisations and societies) is constantly being constructed, modified, selected, checked, suspended, terminated and recommenced in everyday life’. Significantly, such interactions do not take place in isolation and are always in relation to those of, in this case, non-disabled others, or as Plummer (1975: 19, emphasis added) states, ‘interactionism highlights the ongoing construction of symbolic social worlds by men [sic] in *interaction with each other*’. Thus, Brickell (2006: 416) argues, it is through these ‘meaning laden interactions that individual and collective identities develop’. For

example, Katie Ball (2002: 170), a disabled activist, describes how her sexual identity and self were constructed primarily through interactions with others:

> ‘Talk about close encounters of an ableist kind. I’ve been told by men that my vagina is ugly, that they can’t fuck me because of my disability, that fucking me must be like fucking a rag doll, that they’d love to have a relationship with me, but that they can’t handle the sight of my body. Most guys say they’ll come over, and never show up. I’ve had guys come over, stand around in obvious discomfort, and then invent some lame excuse to go back to their car, never to be seen again. Two of them turned up one night. They rang me from their car, got me to come out into the street, and then shot through [left] as soon as they saw me.’

My intention of including Ball’s brutally unrestrained writings here is to illustrate, quite literally, the ways in which sexual identity and the self, and the potential meanings these have for disabled people, is as much produced through interactions with others than through wider discursive constructions of disabled (a)sexualities (which often give birth to the disablism above). Ball’s sexual self was, at that point in her life, constructed and located within and through these negative intimate interactions with non-disabled men, and the inherent disablism (and ableism) within these everyday social interactions had significant psycho-emotional consequences that shaped her sexual self for the majority of her young adulthood. Furthermore, one cannot separate Ball’s experience from her identity as a disabled *woman*. The fact her impaired body was objectified and ridiculed for its deviation from normative feminine bodily beauty aesthetics marks how her gender is a part of her everyday reality and her experiences of disablism in this context (Thomas 2001).

Therefore, while this is a literal example of the ways in which we collate, organise and mediate meaning through our participation in the social world, it does re-emphasise the 'real' gendered lived experience of living within ableist sexual norms that not only serve to Other disabled sexualities, but form the aetiology of the disabled sexual self.

Emanating from an symbolic interactionist perspective is script theory (Gagnon and Simon 1969). Gagnon and Simon (1974: 19) propose sexual scripts are,

> 'involved in learning the meaning of internal states, organizing the sequences of specifically sexual acts, decoding novel situations, setting the limits on sexual responses, and linking meanings from non-sexual aspects of life to specifically sexual experience'.

Thus scripts are 'sets of socially constructed guidelines people use to direct their behaviour and social experiences' (Dune and Shuttleworth 2009: 98). Gagnon and Simon (1974) propose three levels of script: *cultural scenarios*, 'that provide larger frameworks and roles through which sex is experienced (Kimmel 2007: xii); *interpersonal scripts*, 'that represent the routine patterns of social interaction that guide behaviours in specific settings' (Kimmel 2007: xii) and '*intrapsychic scripts'*, the suggestion that 'social action is always conducted with an on-going internal dialogue about internalized cultural expectations' (Kimmel 2007: xii). Jackson (1999: 41) argues that scripting is distinctly gendered; 'men and women have learnt to be sexual in different ways, sexual drama are scripted for actors who have different sexual vocabularies of motive and different orientations to and expectations of sexual relationships'. Thus, Jackson argues (1999: 9), where other forms of social constructionism have largely overlooked gender, interactionist script theory

‘foregrounds gender as central to the scripting of sexuality, the complex co-ordination of bodies and meanings which sexual relations entail’ (see also Ramazanoglu 1993).

Dune and Shuttleworth (2009: 99) argue that ‘script theory dictates that sexual scripts are created through a person’s involvement in cultural, interpersonal and intrapsychic scripts’. However, if a person’s involvement with sexual scripting is based upon a notion of normative (gendered) sexual socialisation or the learning of sexual behaviours mediated through normative encounters and interactions, then it is likely that disabled people may have been denied access to these social arenas and therefore disabled sexualities (and the multifarious forms they can take) may conflict or be unrecognisable within dominant ‘traditional sexual scripts’ (Denov 2003) or, more likely, may remain ‘unscripted’ (Laws and Scwartz 1977). For example, Jackson (1999: 39) states that during adolescence people learn the dominant scripts that ‘govern adult sexual behaviour’ which provides them with ‘a sexual vocabulary of motives’. Thus, the significant exclusion that many young disabled people from normative adolescent social experiences and spaces where such scripts are likely to be learned, organised and internalised, can be understood through a symbolic interactionist account of why many people may lack the language of love (Shakespeare et al 1996). As Gagnon and Simon (1973: 19) state, ‘without the proper elements of a script that defines the situation, names the actors, and plots the behaviour, nothing sexual is likely to happen’.

Dominant sexual scripts perpetuate normatively gendered and ableist ideals and thus, I suggest, are ‘written’ for non-impaired bodies. For example, Sakellariou’s (2006: 108) research found that following spinal cord injury men struggled to

articulate their new sexual identity within the dominant scripts of conventional male sexualities: 'they are torn between a social script that does not bear any resemblance to their life and a personal will that contradicts the social imperative of asexuality'. Additionally, Dune and Shuttleworth (2009: 100) identify what they call the dominant 'sexual script of spontaneity', which sees spontaneity as *necessary* for successful sexual satisfaction and which may lead to dissatisfaction if it is absent. This negatively impacts upon those who may have difficulty experiencing spontaneous sex, such as people with impairments (Dune and Shuttleworth 2009; see Gillespie-Sells, Hills and Robins 1998). Thus 'hegemonic sexual scripts, and efforts to fulfil the expectations of sexual spontaneity can produce barriers to the expression of their sexuality' (Dune and Shuttleworth 2009: 105).

Critical Queered Sexualities and Sexual Selves

As seen in the first half of this chapter, critical disability studies interrogate and problematise hegemonic normalcy – its politics, its power, its language and its identity (Wilchins 2004) in similar and overlapping ways to queer theory, and many disability scholars have acknowledged queer theory's contribution to a radical disability studies agenda (Sherry 2004; Corbett 1994; McRuer 2006; Sinecka 2008; Breckenridge and Vogler 2001). As Goodley (2010: 41) states, there is 'a synthesis of queer and disability theories'. In this section, building on the social constructionist approaches above, I consider the relevance of queer theory and its radical agenda to disabled sexualities.

Sherry (2004: 769) identifies similarities between the experiences of queer people and disabled people: 'familial isolation, high rates of violence, stereotypes and discrimination, and the difficulties associated with passing and coming out'; and

that both activist movements 'reject pathologisation, politicise access, and use humour and parody as political tools'. Moreover, they share distinct theoretical similarities such as: 'their debt to feminism, their opposition to hegemonic normalcy, their strategic use of universalist and minority discourses, their deconstruction of essentialist identity categories and their use of concepts such as performativity'. Sandahl maintains that 'as academic corollaries of minority civil rights movements, queer theory and disability studies both have origins in and commitments to activism' (2003: 26). She states that,

> 'both have been pathologised by medicine; demonised by religion; discriminated against in housing, employment and education; stereotyped in representation; victimised by hate groups; and isolated socially, often in their families of origin. Both constituencies are diverse and therefore share many members, as well as allies. Both have self-consciously created their own enclaves and vibrant sub-cultural practices.' (Sandahl 2003: 27).

In addition, Sherry (2004) cites other similarities - both 'flaunt', that is, seek to reclaim and redefine the language which at the same time oppresses them, and both have exclusions to their movements. For example, queer movements have excluded non-homosexuals which is 'very problematic in particular for transgender people and others who are marginalized by heteronormativity but whose sexual practices may not equate with a queer identity (Sherry 2004: 776). Similarly, disability rights movements have historically distanced themselves from other minority groups for fear of association, for example, people with HIV/AIDS, despite AIDS activism and disability rights movements being synonymous and 'inextricably bound' (McRuer

2002: 225); and more recently with fat activism which has sought to highlight the overlaps between the social experiences of disability and fatness, and the similar treatments of fat bodies and impaired bodies in fat-phobic ableist cultures (Cooper 1997; Aphramor 2009; Chan and Gillick 2009). Furthermore, this exclusion continues *inside* disability rights movements (see Deal 2003); for example, some physically disabled activists have long excluded those affected by mental ill health and mental health system survivors (see Beresford et al 2002) from the movement, along with those with learning disabilities.

With regards to sexual categories, the true usefulness of queer approaches comes when problematising the strict boundaries of both hegemonic normative sexuality and gender categories which, I propose throughout this thesis, particularly alienate and Other disabled people with impaired bodies. Shildrick (2007: 40) states that theorists who engage with queered disability studies, 'are increasingly problematising the conventional parameters of sexuality, in order to explore non-normative constructions of sexual identities, pleasures and agency that more adequately encompass multi-farious forms of embodied difference'. Thus queer facilitates thinking about disabled sexualities and gender identities in terms of their revolutionary potential which is, Rembis (2010: 54) argues, not only lost via a social model (constructionist) approach, but is further grounded within (oppressive) traditional gendered constructs:

> 'Ironically, much of the social research on disabled sexuality and many of the pronouncements of disabled subjects, both of which have been concerned with 'defying sex/gender stereotypes' and challenging

> powerful cultural myths concerning disabled people, have served to reinforce, rather than challenge the heterosexual matrix'.

Hopefully, utilising queered critical disability studies enables us to challenge taken-for-granted hegemonic genders, and thus conceptualise disability as a potential threat to the heterosexual matrix (Butler 2003). Moreover, Rembis proposes that the sexual futures of disabled people must be based upon Davis' (2002: 31) notion of 'dismodernism' whereby 'impairment is the rule and normalcy is the fantasy':

> 'By loosening the conceptual ties that bind our perception of 'normal' relationships, we in turn open up new ways of thinking about sex and beauty. 'Dismodernism' has the potential to transform a society where people are expected to live a life free of pain and discomfort, a society where strict social norms concerning beauty and physical fitness compel people to alter their bodies in drastic, often violent ways, through surgery, dieting, exercise, and other 'cosmetic' procedures, a society where youth, physical prowess and a very narrow idealization of heteronormative sexual allure are highly valued and sexual performance is wedded to one's physicality. Sex, eroticism, and desire, will look very different in a 'dismodern' world where 'cosmopolitanism,' interdependence and a reliance on technology are the 'norm.' In a 'dismodern' world, dis/abled bodies will become 'sexy' bodies.'

Therefore it is not enough to merely assimilate disabled people, their (possible) alternative sexual practices, and their anomalous embodiment into a hegemonic heteronormativity which can't house them; instead, what Rembis is proposing for the emancipation of disabled peoples' sexual futures is a total rethinking of human

sexualities according to a dismodernist ideology. At the same time, a dismodernist society would emancipate the sexualities of *all* people. However utopian and improbable, Rembis does envision a sexuality in ways that doesn't support the dis/abled binary and thus challenges sexual normalcy. But he offers few immediate strategies for disabled people.

Additionally, the proposition to totally deconstruct gender, as many queer theorists advocate, is problematic, and sizeable tensions exist between feminism and queer theory on this basis (see Jeffreys 1994; Smyth 1992). Queer theory, while by no means a 'unified perspective' (Jackson and Scott 2010: 19), makes sexuality its primary object of analysis rather than gender. For example, it has been accused of: overlooking the specifically gendered experience of sexual dissidents; neglecting the material conditions of women's lives through ignoring material and structural inequalities (Jackson 1999); overlooking the oppression of lesbians and 'discriminating against the interests of lesbians' (Jeffreys 1994: 459); acting as masculinist theory in costume (Smyth 1992); reducing gender to lexicon and overlooking embodiment (Bordo 1993) and its distancing the category of woman from everyday lived reality (Fraser 1999). Furthermore, not only does adopting a queer conceptualisation of gender risk disregarding much of the work that disabled feminists have put into locating gender within analyses of disability, but one could ask whether utilising an approach which destabilises identity in the way that queer theory does is appropriate when theorising about the sexual lives of disabled people many of whom are, in ableist culture, striving for the seemingly 'fixed' sexual and gendered identities of non-disabled men and women. Thus, there may be costs in building on queer theory in relation to disabled sexualities, if it means neglecting

gendered categories and experiences. Therefore, as stated earlier in this chapter, through my empirical investigations I will question the value of such radical perspectives in theorising disabled peoples' lived experiences of sexual and intimate life.

To sum up the conceptualisation of 'sexuality' that underpins my research, then, through this latter half of the chapter I have shown it to be comprised of an amalgamation of a range of critical and traditional social theories. For example, a broad constructionist lens offers a necessary post-biological understanding of sexuality that de-pathologises disabled sexualities (and people), removing them from being merely medicalised 'subjects and fetishized objects' (Shakespeare et al 1996: 03). Social constructionism redefines sexual life as inherently socially produced and mediated. However, as Dewbury et al (2004: 151, my emphasis) state 'the importance of social constructionism lies not in the fact that X is a construction, but in *how* it is constructed'. Thus, through post-structuralism, (largely Foucauldian theory), one can consider the ways in which disabled sexualities are both produced and shaped via multifarious discourses emanating from multiple social spaces and institutions, and the means through which polymorphous powers contribute to this shaping.

However, I have outlined possible tensions between post-structuralism's discursive body and a critical realist requirement of acknowledging bodily materiality. While the discursive (sexual) body having 'no pre-given materiality' (Tremain 2000: 296) offers a fundamental challenge to the problematic (ableist) notion of a *naturally* impaired body, it simultaneously constructs a body which discounts the embodied lived 'hard physical realities' (Wendell 1996: 45) of

impairment and the meaning of this type of embodiment, both of which are likely to interact with disabled peoples' experiences of sexual opportunities, identities, and intimate relationships and their possible resistance to the ableist sexualities ascribed to their bodies. I have (tentatively) expressed similar caution about certain areas of critical and queer perspectives that together form the necessary interrogation of ableist heteronormativity and the 'able' sexual body that lies at the very heart of my thesis. It is not that I discredit the revolutionary sentiment within such approaches, nor doubt the commitment to political emancipation that underpins them; rather my worry is that positioning emancipation as occurring *only* through, for example, 'dismodernist' (Davies 2002; Rembis 2010) sexual futures, suggests that no empowerment or emancipation can be achieved through the current ableist social world, and simultaneously overlooks the individual sexual agency and resistance that disabled people may already exercise, or can potentially exercise, within their sexual lives.

Finally, in contrast, symbolic interactionism and script theory provide a micro-social focus upon subjectively constructed experience and individual meaning, through which disabled peoples' sexual agency and resistance in relation to other people in day to day interactions can be made visible (see Weeks 1986). This interactionist lens facilitates much of my inquiry: as well as locating and marking possible sexual agency and power, attention is given to the everyday interactions that contribute to the sexual self and towards that which, for disabled people, can serve as the very site of their experiences of asexualisation and sexual oppression and thus their lived experiences.

Conclusions

In sum, this chapter has provided an overview of the diverse theoretical foundations upon which my research draws, supporting Shakespeare and Corker's (2002: 15) assertion that 'the global experience of disabled people is too complex to be rendered within one unitary model or set of ideas'. I have outlined the contributions of a range of theoretical perspectives on disability, impairment, and sexualities and have highlighted the tensions and synergies between them. I have offered a history of the social model in relation to disabled sexualities and its subsequent developments towards acknowledging impairment, embodiment and identity. Utilising a range of critical social theories ensures that my explorations are not restricted to social, political, and economic processes, but that they equally include the 'psychological, cultural, discursive and carnal' (Meekosha and Shuttleworth 2009: 50). However, at the same time I question the application of certain critical approaches to disabled sexualities in isolation, for fear of privileging theory, intellectualism and politics over everyday lived realities. My intention in this thesis, then, through my own empirical investigations, is to contribute to these bodies of literature, exploring how far my data supports their view of the key possibilities and constraints, and their conceptualisations of disabled sexuality and agency.

Methodology

Introduction

Approaches to mainstream disability research have long been criticised by disabled people, disability organisations, and disability rights movements: terms such as 'rip off' (Oliver 1997: 15), 'parasites' (Hunt 1981), and 'the rape model' (Reinharza 1985) have been applied. The paradigm of 'disability research' therefore remains a strongly contested one (Kitchen 2000), and there is considerable literature on its researchers, methodologies and epistemologies (for example, see Oliver 1992; Barnes 1992; Barnes and Mercer 1997; Zarb 1992; 1997; Bricher 2000; Tregaskis and Goodley 2005; Branfield 1998; Duckett and Pratt 2001). Significantly, much of disabled peoples' condemnation originates from the ways in which, up until recently, research has focused on disabled people only as medical and social problems. Oliver (1992: 101) argues that 'research, on the whole, has operated within frameworks and sought to classify, clarify, map and measure their dimensions'. Rioux and Bach (1994) suggest that disabled peoples' caution can also be attributed to the ways in which research (from scientific and other disciplines) has been used in the past; for example, to affirm segregationist policies and eugenics movements, and deny human rights. Another key criticism is that disability research has done little to challenge the oppression experienced by disabled people (Davis 2000; Oliver 1992; Barnes 2003) and thus has not 'contributed directly enough to the emancipation of disabled people from oppressive social practices' (Duckett and Pratt 2001: 815).

Such dissatisfaction with 'traditional' epistemological, ontological and methodological approaches has resulted in scholars debating possible alternatives. This has resulted in, as Hodge articulates (2008: 29), disability research being

‘conducted within a highly politicised ‘hotbed’ of competing paradigms and principles’. The emancipatory approach (Oliver 1992) is a fundamental response to such failings. Rooted in a rejection of positivist and interpretivist epistemologies on the basis that they ‘are not immune from characterisation of research alienation’ (Oliver 1992: 101), Oliver (1992: 100) argues the case for a new direction in disability research which is ‘about facilitating the politics of the possible by confronting social oppression at whatever level it occurs’. He argues for ‘a recognition of and confrontation with power which structures the social relations of research production’ (Oliver 1992: 110). Thus, an emancipatory approach calls for a change in the social relations of research production in order to create research that is relevant and meaningful within the lives of disabled people. Therefore, the emancipatory approach relates to more than methodological concerns and proposes ‘fundamental changes to the ways in which research is planned, implemented and disseminated’ (Barton 2005: 319). Participatory approaches to disability research are borne out of similar concerns. While emancipatory research (Oliver 1992) seeks ‘positive’ *societal* change, participatory approaches seek ‘positive’ *individual* change through disabled peoples’ participation (Kitchen 2001). According to French and Swain (2004: 10), participatory research is ‘essentially about establishing equality in research relationships, that is, giving more ‘say’ in research to people who are more usually subjected to research’.

The methodological approach guiding my research does not offer emancipatory (Oliver 1992) or participatory approaches in their *purest* form. This is not least because achieving these in a genuine and authentic way ‘is a long, hard road’ (Lloyd et al 1996: 305), but also because of their respective criticisms (e.g.

Shakespeare 1996, 1997; Kitchen 2000; Beazley, Moore and Benzie 1997). I take particular issue with emancipatory research, agreeing with Shakespeare's (1997: 250) evaluation: 'I have real concerns about such approaches and their ability to achieve 'vast change' within the lives of disabled people, since grandiose claims for the revolutionary potential seems to be over-optimistic'. Instead, I aimed to adopt the spirit and ethos of each approach, and remain true to the identifiable central tenets of consultation, accessibility, empowerment and relevance. The research methodology is located within overarching interpretivist epistemology, conceptualising that individuals and groups construct their own versions of reality' (Gilbert 2001: 33), and constructivist ontology 'that asserts that social phenomena and their meanings are continually being accomplished by social actors' (Bryman 2008: 692). Thus, both a (qualitative) narrative production and analysis of data considered participants' sexual stories as storied forms of their own lived experiences.

This chapter is divided into four parts. Firstly, the research design is outlined. Secondly, the ways in which participants were accessed and sampled together with a detailed overview of participants is provided. Thirdly, the chapter provides an explanation of producing and analysing sexual stories. The final part of this chapter considers the ethical considerations required within research of this kind and offers a reflexive discussion as to my own subjectivity as the researcher, and the practical and emotional challenges that occurred throughout the fieldwork period.

Research Model and Design

The central tenets of consultation, accessibility, empowerment and relevance formed the aetiology of my research methodology. Its guiding principles included: that the research process be developed and designed in consultation with disabled

people; that the research process become a truly accessible space; that opportunities for empowerment via participation and story-telling could be offered, and that these operate alongside a commitment towards ensuring that the research and its findings are relevant and meaningful to disabled people both within and outside of the academy. The origins of this approach can be found within two areas of my biography and subjectivity: first, as a disabled person who has lived within and through disabling environments. As Shakespeare states (1997: 187) 'our own lives and feelings are very relevant to the [research] process'. The second was through my former employment as a facilitator for disabled peoples' service user consultation groups, an offshoot service provided through a local Centre for Integrated Living. Such consultation groups, funded as part of local authority social care planning and development, routinely became spaces, despite their avowed aims, where disabled peoples' voices and expert knowledges were seldom understood, listened to, or valued (see Bewley & Glendinning 1994). These 'main ingredients' of my research design gave birth to an egalitarian research process which sought to position disabled peoples' voices as central. The initial section of this chapter will concisely detail the research design and outline the variety of practices through which my research tried to adhere to its guiding principles.

Consultation and Participation: The Research Advisory Group

In order to position the disabled person as expert and to facilitate disabled people's participation and voice within the research, a Research Advisory Group made up of local disabled people was established. The idea for an advisory group was based upon Kitchin's (2000: 45) work on researched disabled people which found that the 'ideal' model proposed by disabled people for use within disability

research is ‘an equal-based, democratic partnership between disabled people and disabled/non-disabled academics’. The purpose of the Research Advisory Group was to guide the research process, offer expert knowledge, and ensure that the research was accessible, engaging and empowering for the individuals who took part. Establishing the group also contributed towards efforts to destabilise the traditional power imbalances between the researcher and the researched, and go some way towards improving how disabled people engage with social research, ensuring that they see it as of value and that which is transferrable to the reality of their lived experiences.

Research Advisory Group members were recruited through a wide mail-shot to disability organisations in Buckinghamshire, England, where I live. Although research participants came from all over the UK, for financial and access reasons the Research Advisory Group was restricted to local membership. The mail-shot (see appendix 1) was distributed to local disability organisations: the MK Scope Resource Centre, Milton Keynes Centre for Integrated Living, MK MS Therapy Group, Different Strokes, Royal National Institute for the Deaf MK, the Royal National Institute for the Blind Resource Centre MK, the Physically Disabled and Sensory Impaired Consultation Group (an independent consultation group based in Milton Keynes), and the Fibromyalgia MK Support Group. Despite this scale of advertising, just four local disabled people attended the introductory session which took place in August 2009. Although initially disappointing, this low turnout concurs with existing evaluations of emancipatory research approaches which suggest that while disabled people may be favour of inclusive approaches to research, very few may have the time or inclination to take part (see Kitchen 2000). However the individuals involved

made up a strong core group who were committed to the project. A further three additional members joined for the post-field work follow-up meeting which took place in August 2010. As well as physically meeting up, contact with group members was on-going throughout the research process via email. In addition, while the group originally met in a local meeting room in the Milton Keynes Centre for Integrated Living, group members felt at the first meeting that any following meetings should be more informal. Thus following meetings took place at a local public house at its members' request. The group was made up of two males and five females who were all white British, aged between 45 - 64 years, and had either acquired or congenital physical disability. Notably, all but one had involvement within local disability movements or organisations.

The group ran in conjunction with the research from the stages of research design and is not due to cease until the creation of a dissemination plan following thesis submission. While a partnership model is privileged within both emancipatory and participatory approaches, collectively the group established its own role and aims. At the initial meeting it was felt by group members that the positionality of members as *partners* was both unwanted and unrealistic. Instead, group members favoured a supportive and collaborative role whereby they could impart expert knowledge, help set the research agenda, and have 'the opportunity to correct misrepresentations and influence the direction of the research' (Kitchen 2000: 38) without taking on the responsibility or accountability of being a partner. Group members also had little interest in the more technical aspects of research. For example, they did not want to be involved in a joint analysis of data - outlined as a central practice in true partnership research (Whitaker & Archer 1994). Instead,

group members were content that my own knowledge and expertise as a researcher be responsible for the more technical elements of the research process.

Disabled peoples' participation has its history in the promulgation of the National Health Service and Community Care Act (1990), which 'made consultation with service users a legislative duty for local authorities' (Car 2004: 5; see also Lloyd et al 1996). Since this development, disabled people have been widely involved in government policy and planning in many areas of social life. However, this has not always been successful; as Barton (2005: 325) states, 'there is the need to increasingly recognise and more thoroughly understand and practice the art of 'listening' to the voices of disabled people'. Therefore, rather than a tokenistic space, my focus was in *listening* and utilising effectively the expert knowledge communicated by the group. Significantly, the group met its aims, setting the research agenda and shaping the research considerably. For example, at the commencement of the research, members provided crucial social networks and ideas for both accessing and recruiting participants. Much of the accessibility of the research methods and materials can also be attributed to the group (discussed later). Importantly, the group's laughter, support, guidance, and enthusiasm fostered a relaxed space through which I learned to speak to disabled people about sex and relationships. In particular, some group members shared their own stories as a prerequisite to designing how the stories of others could be collected and used. Many of the topics that later formed the body of the interview schedule were borne out of such discussions. Therefore, the group assisted with research design and planning; the production of research materials; advised on matters of sampling; and, in the most recent meeting, enabled me to talk through my experiences of carrying out

fieldwork and provided thoughts on preliminary findings.

Empowerment through Narratives: Telling Sexual Stories

The sexual stories of participants in my research are told by disabled people only, echoing the initiatives found in feminist and anti-racist methodologies which 'place the minoritized at the centre of analysis' (Dei and Johal 2005: 2), where their 'subjective experiences and voices' are prioritised (Pole and Lampard 2002: 290). Historically, existing research into disabled peoples' sexual lives has, paradoxically, mainly been on those who govern the sexual lives of disabled people: social workers, doctors and other health professionals, family planning clinics (Anderson and Kitchen 2000), teachers (Wolfe 1997), socio-sexual educator-counsellors (Bullard and Wallace 1978), and support workers (Chivers and Mathieson 2000; Hamilton 2009). It has also taken place through works which, I suggest, dilute disabled peoples' voices by including their voices only alongside those of non-disabled people (Cheausuwantavee 2002; see also Branfield 1998). Such research, argues Shuttleworth (2010: 3), has been concerned predominantly with '[sexual] function and individual adjustment' and principally relies on quantitative methodologies. Thus, this work has done little to empower disabled people and foster their sexual cultures. Therefore, in order to encourage empowerment I wanted my research to follow the best practice set out by research from a disability rights perspective which has privileged disabled peoples' voices through providing them a platform from which to tell their own sexual stories (see Davies 2000; good examples are: Shakespeare et al 1996; Shuttleworth 2000; Leibowitz 2005; Li and Yay 2006; Parker and Yau 2011; Pearson and Klook 1989; Sakellariou 2006, 2010; and Mona et al 1994).

In addition, I conceptualised both personal and political empowerment to be achievable through the process of story-telling itself. What Ken Plummer (1995: 15) calls ‘sexual stories’ are ‘socially embedded in the daily practices and strategies of everyday life’. Langellier (2001: 700) argues that ‘personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities, and ‘get a life’ by telling and writing their stories’. Thus, story-telling can be, as Plummer (1995: 150) argues, instrumental within social and political change:

> 'Rights and responsibilities are not "natural" or "inalienable" but have to be invented through human activities and built into the notions of communities, citizenship and identities. Rights and responsibilities depend upon a community of stories which make those same rights plausible and possible. They accrue to people whose identities flow out of the self-same communities. Thus it is only as lesbian and gay communities started to develop and women's movements gathered strength that stories around a new kind of citizenship became more and more plausible. The nature of our communities - the languages they use, the stories they harbour, the identities they construct, the moral/political codes they champion - move to the centre stage of political thinking'.

Plummer’s (1995) emphasis becomes even more pertinent when considering that disabled peoples’ social and political histories are defined by their silenced voices. I propose, then, that the act of *telling* sexual stories is fundamental towards the development of disabled peoples’ sexual cultures which, despite 40 years of political action, remain embryonic (see Siebers 2008), and their emerging sense sexual citizenship (Plummer 2003; Wilkerson 2002).

Accessibility

In order to facilitate accessibility, a multi-method and multi-format approach was adopted whereby participants could take part in a semi-structured interview or write their sexual stories. Both of these research methods facilitated disabled participants' control over their story-telling, and both were available in multiple formats to suit participants' individual requirements and/or preferences. While this approach is discussed in further depth later in the chapter, I note here that it was borne out of early discussions with the Research Advisory Group (RAG) as both practically and politically pertinent. The group echoed the need for an accessible research method whereby participants had 'choice' within their participation. Moreover, it was considered politically important to recognise the diverse ways in which disabled people communicate. Thus, group members felt that the methodology should reflect political and policy movements towards diversity and equality; for example, ensuring that disabled participants did not have to fit into designated categories or existing research frameworks, but should be able to take part in a process designed specifically to meet their needs and preferences.

Essentially, this accessible approach to data collection allowed the stories of those who, I argue, if only traditional data collection methods had been available, would not have taken part. For example, five young people (30 years and under) in the sample chose to be interviewed via instant messaging, not only because it is a primary way in which young people in contemporary society communicate, but because it offered informality which put them at ease and provided absolute anonymity, even to the researcher. It was also chosen for practical reasons such as not physically being able to get to or take part in an interview (because of

impairment, access, or bad weather) and because it was a means of taking part without participation becoming known to personal assistants, carers, partners and parents; Skype interviews were chosen by two participants for similar reasons. In addition, those who did not want to be interviewed in person, but for reasons of limited dexterity may have found an instant messaging interview (based on typing) difficult, could be interviewed by email (often spread over many months); additionally, one male participant chose an email interview due to severe speech difficulties. Another five participants chose to write or '*speak'* their sexual story at their own pace through a keeping a journal. For example, a Deaf participant who was concerned at having a BSL interpreter present at a face-to-face interview because of the impact on confidentiality chose to keep a participant journal which enabled her to write her story (meaning no interpreter was needed). Notably, many participants made method and format choices purely out preference (rather than for accessibility reasons), highlighting that social research methodologies generally could benefit from privileging participant preferences and comfort - particularly within the researching of sensitive topics (see Lee 1993; Renzetti 1993), 'where research intrudes into the private sphere or delves into some deeply personal experience' (Lee and Renzetti 1993: 6). Talking about sex and relationships was understood to be a difficult and often emotional task which could, for some, be more difficult discussing in person. Thus, offering alternative formats reduced the possible embarrassment and shame of sexual story-telling and, I argue, made the process more likely to be experienced as empowering. Ultimately, going beyond standardised and more traditional research methods enabled a reach further into the target population. It also ensured respect for the diversity of participants and their choices, and thus a chance

to obtain the stories of people who are often under-represented in social research, resulting in a wider and more diverse sample.

Relevance

Barton (2005: 318) proclaims that 'relevant research is essentially transformative, informative, contributing to the collective experience and understanding of disabled people over the ways in which disability is socially produced.' Thus, basing the research upon a theoretical framework that acknowledged impairment and embodiment, conceptualising disability as a combination of 'biological, social, and experiential components' (Wendell 1996: 23), was a way in which disabled peoples' contextualisation of their own lived experiences of non-normative embodiment and gender and sexual identities could be understood. This model of disablement was a further reason why the research could not be unequivocally emancipatory, because the only epistemological foundation for an emancipatory research production is the social model (Stone and Priestley 1996: 706).

Another way of ensuring that the research is meaningful and relevant to disabled people will be through a thorough dissemination of findings within both non-academic and academic contexts. The majority of disability research is published purely within academic or governmental contexts meaning the findings themselves are inaccessible and thus fail to transfer to the reality of disabled peoples' lives. This results in disabled people knowing very little about the sociological research which is about them, and some of which shapes the policies and initiatives that govern their lives. Barton and Oliver (1997) argue that this denies disabled

peoples' communities the prospect of taking action on findings in a positive way. Through producing more accessible and understandable versions of her research on women's relationships with medicine and health (especially for those the research was about), Oakley went some way towards solving this problem (1993); Shakespeare (1997) also works on this basis (see also Goodley and Runswick-Cole 2011). A more recent disability and sexuality text edited by Shuttleworth and Sanders (2010) usefully provides accessible summaries at the beginning of each chapter in order to reach out to a non-academic audience. Dissemination within non-academic spaces will be planned in conjunction with the Research Advisory Group following thesis submission.

A two year post-doctoral fellowship has been secured which will fund publication of findings (in a variety of formats) within disabled peoples' networks both in British and North-American contexts. While being based at Ryerson University, Toronto, Canada, and disseminating to British audiences may pose a logistical problem, a useful solution can be found within the work of Goodley, Campbell and Runswick-Cole (2011) who produced 'impact summary cards' that efficiently and clearly set out key findings from their research in an accessible way and which are available online and can be distributed easily to wide audiences. Moreover, while I aim to work more directly with disabled peoples' networks in Canada in order to disseminate my findings, the internet provides a functional space through which I can reach a potential global audience. Websites as research, dissemination and communication spaces are becoming more visible precisely because of the scope offered and the ability to engage with many different audiences; good examples are Goodley and Runswick-Cole's (2011) 'Does Every Child Matter,

Post-Blair? The Interconnections of disabled childhoods' website, and Throsby's (2011) 'Becoming a Channel Swimmer' website.

Access, Sampling and Participants

Access

Accessing research participants took various routes. The purpose of this was to gain participants with a variety of physical and/or sensory impairments, genders, ethnicities, socio-economic backgrounds, sexual preferences, disability types, origins (e.g. acquired or congenital) and severities, thus being sensitive to the heterogeneity of disabled people which is often omitted within much disability research (Thomas 2002). Predominantly, participants were accessed via advertisements posted on the 'online forums' or 'chat spaces' within the websites of large disability charities, smaller disability organisations and through one private company: for example, Scope (Cerebral Palsy and pan-disability), Muscular Dystrophy Campaign, Royal National Institute for Blind People, Royal National Institute for Deaf and hard of hearing people, Spinal Injuries Association, Deaf Village, The Stroke Association, and Spokz (user-led disability equipment company/disability sex aids/toys supplier). These forum posts were also distributed via email to the member lists of Independent Alternatives, a London-based Personal Assistant organisation, and REGARD, a lesbian, bisexual, gay and transgender and disability organisation. Participants were further accessed through advertisements or feature articles published in the popular disability press, for example, *Target MD* (flagship publication of the Muscular Dystrophy Campaign) (appendix 2), *The Hearing Times* (a D/deaf newspaper) (appendix 3), and *Inside* (appendix 4), a magazine produced by Outsiders, a sex and disability self-help organisation. Participants were also accessed through a sex and

relationship workshop I conducted for Muscular Dystrophy Campaign at its Adult Information Day; via the Research Advisory Group; through leaflets to a young persons' respite care hospice (see appendix 5); and through a presentation given to disabled staff and volunteers at the Milton Keynes Centre for Integrated Living (MK CIL).

Engelsrud (2005: 267) contends that the researcher's body can be both an 'asset and limitation to the acquisition of knowledge'. Significantly, it was made transparent to prospective participants through advertising and recruitment that a disabled researcher was conducting the research. While Barnes (1992: 121) argues that 'having an impairment does not automatically give someone an affinity with disabled people, the experience of impairment is not a unitary one', it could not be denied that openly identifying as a disabled person does help with accessing and recruiting participants. I suggest that this was particularly pertinent given the sensitive nature of the research topic. For example, participants often said in their interview that they would not have taken part if I had been a non-disabled researcher. One organisation, that assisted with accessing participants, even requested my disability (and impairment) status was made more explicit on advertising literature for fear that it would get a negative reaction from its members who are regularly called upon by non-disabled researchers. However, there are inherent ethical considerations to making my status so explicit, and these are discussed fully in the ethics section in the latter half of the chapter.

Sampling

My initial sampling criteria specified that individuals had a physical and/or sensory impairment, were aged between 18 – 25 years, and were willing to share

their experiences for the purposes of research. Such a limited age range was chosen because I felt that individuals born after the establishment of disability rights movements and pertinent policy changes (e.g. the 1990 Community Care Act which enabled disabled people the right to live within the community) and subsequent developments towards equality (e.g. the Disability Discrimination Act 1995) would have a very different lived experience of disability than those born prior to these important socio-political changes. However, this upper age limit was quickly removed. Initially, this was because access to young peoples' disability groups proved difficult, since the ages typically represented through these groups were often under 18, and interviewing would have raised issues surrounding consent. Consequently, specifically accessing individuals aged 18-25 years (therefore those who did not appear to participate in adult groups, and were too old for young peoples' groups) was difficult. Secondly, through early interviews with participants of a range of ages my assumption was recognised to be erroneous. Hence I decided to seek participants of varied ages which would also enable interesting analytical possibilities for comparisons.

The research remained exclusive to individuals with physical and sensory impairment. While this could be considered a non-inclusive approach to researching disability, and which reinforced the hierarchy of impairment (Chapkis 1986; Shakespeare 1996; Deal 2003), excluding other impairment categories, such as people diagnosed with learning disability and people with mental illness and/or mental health histories, were for important reasons. The first was that research into the sexual subjectivities of people with physical and sensory impairment, (particularly those with sensory impairment), is relatively under-theorised in

comparison to the extensive empirical research into the sexual lives of people diagnosed with learning disability, and to a lesser extent, people with mental illness and/or mental health histories. Much of the focus of learning disabled peoples' sexual lives has been upon capacity to understand sex and relationships (McCarthy 1996, 1999; Yacoub and Hall 2009; Dukes and McGuire 2009; Rogers 2009); consent to sexual acts/relationships (O'callaghan and Murphy 2007); management of risk; both to themselves in terms of sexual health (Thompson et al 1994; Rohleder and Swartz 2009) and abuse (Turk and Brown 1993; McCarthy and Thompson 1996; Brown et al 1995; Dickman et al 2005); and risk to others as potential abusers (Lindsay et al 1998; Craig et al 2006; Lunsky et al 2007; Michie et al 2006; Steptoe et al 2006) or as sexual deviants (Cambridge 1996). The sexual identities of people affected by mental illness (or who have a mental health history) are considered in similar ways; for example, sexual health concerns (Tennille et al 2009; Campos et al 2008; Hughes and Gray 2009; Wainberg et al 2007); capacity for relationships (Perry and Wright 2006); sexual isolation (Wright et al 2007); mental health medications and sexual functioning (Clayton and Balon 2009); and as abusers (Friedman and Loue 2007). More importantly, these populations were also not recruited because of serious concerns around protection from harm (see McCarthy 1998) and because I had little experience of working with these populations in comparison to those with physical and sensory impairment (through previous employment). In addition, a preferred analytical focus was upon anomalous embodiment (Shildrick 2002) (non-normative bodies) and experiential accounts of living with and managing the impaired physical body as part of sexual and intimate life.

Participants were sampled using non-probability purposive sampling methods. Besides the advertisements discussed above, some participants were accessed via a 'snowball effect' whereby those who had already taken part recommended participation to others. Interestingly, this snowballing was created through a chance network of young disabled men who have a presence on the internet via forums and blogs where they discuss life as a disabled person, including sex. Not only did being part of this network instigate their participation in the research, it also appeared to link these men after they had taken part through post-participation discussions both online and in person at unrelated disability events. Following an initial enquiry about taking part (see appendix 6), participants were sent an information sheet which detailed the research process through an accessible 'question and answer' style format (see appendix 7). At the same time they were provided with a consent form (appendix 8) and a short questionnaire which asked for basic demographic information and details of impairment (see appendix 9). Prospective participants usually required considerable support through this stage and either withdrew prior to consent, or shortly afterwards, due to the sensitive nature of research topic.

Participants

The accessing, sampling, and recruitment process took place over a period of 16 months, from May 2009–August 2010, and occurred in conjunction with interviewing participants. In total, 26 participants took part in the research; 25 had a physical disability and/or sensory impairment and one, the partner of another participant who took part in a joint interview at the disabled participant's request, identified as non-disabled. Such good access together with wide selection criteria made for a diverse sample containing men and women of all ages from a range of

socio-economic groups, and with a variety of impairments (see table 1). The ages of participants ranged between 20 and 64, with the average age of participants being 35. In terms of gender, more men (n=16) than women (n=10) took part in the research and this gender breakdown is similar to those who first approached me; predominantly more men got in touch than women. It is likely that this is because men, culturally, are more able to talk about sex as part of dominant hegemonic masculine identities. Another possibility may have been that issues of sex and relationships, or (social) barriers to them, are, through prevailing biological discourse, believed to be more 'constricting' for male sexualities and thus is perceived to be more of a legitimate 'concern' for them to talk about. It could also be attributed to extensive advertising and support from the Muscular Dystrophy Campaign (see below) predominantly recruiting participants with forms of muscular dystrophy and related neuromuscular impairments, many of which are more prevalent in men than women.

In terms of impairment types (see table 1), participants predominantly had physical impairments (n=23) with only one person having only a sensory impairment (n=1), and another having both a physical and sensory impairment (n=1). Significantly, sensory impaired participants were recruited through The Stroke Association's TalkStroke forum and *Inside* magazine (a pan-disability publication), rather than through advertising aimed specifically at their impairment group. In addition, due to a national feature article run by the Muscular Dystrophy Campaign's *Target MD* magazine (Stein 2010; see appendix 2), a large number of the physically disabled participants had either Muscular Dystrophy or other neuromuscular impairments (n=13). Other impairments in the sample included Spinal Cord Injury

(n=5), Cerebral Palsy (n=3), and other mobility impairments such as Ataxia, immunity impairment, post-cancer disability, and motor neuropathy (n=3). Of all disabled participants (n=25), 8 had acquired disability (n=8), with the remainder being either (i) congenitally disabled with symptoms experienced since birth (n=11) or (ii) congenitally disabled with later onsets/diagnoses (n=6). This offered a wide range of different experiences of, and interactions with, both disability and impairment in relation to disability origin and diagnosis. Despite 6 participants identifying their impairments explicitly as progressive and life-shortening in nature (outside of the natural progression of impairment exacerbated through ageing), this was seldom a factor to which they referred within their sexual story.

The sample lacked diversity in failing to attract participants from a range of ethnicities and sexualities, and those with sensory impairments. The sample was largely White British (n=22), with just four participants identifying as other ethnicities: African (n=1), British-Asian (n=1) and British-Indian (n=1) and unknown (n=1) (this participant took part in an email interview and did not reveal his ethnicity other than to state he wasn't British). This may have been due to cultural and religious factors making it harder for prospective participants from these ethnic groups to participate, particularly because of the nature of the research topic and also that they are less likely to live alone and therefore worried about confidentiality. In addition, only one participant (n=1) identified herself as a (polyamorous) lesbian meaning that the sample primarily identified as heterosexual (n=25). This was very disappointing because a key aim of the research had to been to alleviate the dearth of information and knowledge around the sexualities of lesbian, gay, bisexual and transgendered disabled people (see Corbett 1994; Blyth 2010;

Davy 2010; Brownworth and Raffo 1999). It may also risk affirming the compulsory heterosexuality ascribed to disabled people (Kafer 2003; Appleby 1992). Similarly, it was an aim to recruit people with sensory impairments because, as Duckett and Pratt (2001) argue, sensory impaired people, particularly those with visual impairments, remain seriously under-represented within research – largely because researchers fail to facilitate simple accessibility requirements such as providing research materials in alternative formats.

Regrettably, advertising at both formal (RNID and RNIB) and informal arenas aimed at sensory impaired people (e.g. Deaf Village), and providing all advertisements, posters, contact, and research materials in both standard and large print, failed to recruit an adequate number of participants with these impairments. Duckett and Pratt (2001) experienced a very slow response rate in their research on visually impaired people and research participation, and report that participants described that the reluctance of visually impaired people to take part in research is based on large numbers being 'hidden from services'. Duckett and Pratt (2001), suggest, then, that this is 'an issue that needs considering when recruiting participants for visual impairment research'. Therefore, it is possible that a longer fieldwork period may have meant a higher recruitment rate of people with sensory impairments.

Table 1: Participant Demographics (all participant names, both in this chart and throughout the remainder of the text, are pseudonyms)

	Name	Ethnicity	Impairment type	Impairment	Age	Sex	Journal/ Interview	Method format	Sexual Orientation	Congenital/Type
1	Jenny	White-British	Physical	Spinal Cord Injured	64	F	Interview	In Person	Heterosexual	Acquired (aged 11)
2	Gemma	White-British	Physical	Immunity Impairment and Bone Cancer	42	F	Interview	In Person	Lesbian	Acquired (onset 16 years)
3	Mark	White-British	Physical	Duchenne Muscular Dystrophy	35	M	Interview	In Person	Heterosexual	Congenital (onset 3 years)
4	Hayley	White-British	Physical	Ullrich Congenital Muscular Dystrophy	31	F	Interview	MSN	Heterosexual	Congenital
5	Bob	White-British	Physical and Sensory	Visual Impairment & Motor and Sensory Neuropathy	58	M	Interview	Email	Heterosexual	Congenital
6	Michael	White-British	Physical	Cerebral Palsy	24	M	Interview	MSN	Heterosexual	Congenital
7	Robert	White-British	Physical	Spinal Muscular Atrophy	26	M	Interview	MSN & Email	Heterosexual	Congenital (onset 18 months)
8	Shaun	White-British	Physical	Spinal Cord Injured	33	M	Interview	In Person	Heterosexual	Acquired (aged 10)
9	Hannah	White-British	N/A	Non-disabled	32	F	Interview	In Person	Heterosexual	N/A
10	Graham	White-British	Physical	Ataxia	52	M	Interview	In Person	Heterosexual	Acquired (aged 20)

11	Pete	White-British	Physical	Athetoid Cerebral Palsy	42	M	Interview	Email	Heterosexual	Congenital
12	Lucille	White-British	Physical	Spinal Cord Injured (tetraplegic)	36	F	Journal	N/A	Heterosexual	Acquired (aged 23)
13	Al	Unknown	Physical	Spinal Cord Injured	46	M	Journal	N/A	Heterosexual	Acquired (aged 23)
14	Grace	White-British	Sensory	Deaf	58	F	Journal	N/A	Heterosexual	Acquired (aged 6 – progressive hearing loss)
15	Tom	White-British	Physical	Cerebral Palsy	28	M	Interview	In Person	Heterosexual	Congenital
16	Phillip	White-British	Physical	Spinal Cord Injured (paraplegic)	38	M	Interview	In Person	Heterosexual	Acquired (aged 35)
17	Rhona	White-British	Physical	Spinal Muscular Atrophy Type 2	31	F	Interview	Email	Heterosexual	Congenital
18	Abram	British-Indian	Physical	Spinal Muscular Atrophy	35	M	Interview	Skype	Heterosexual	Congenital
19	Kadeem	British-Asian	Physical	Muscular Dystrophy	28	M	Interview	MSN	Heterosexual	Congenital (onset 6-7 years)
20	Sally	White-British	Physical	Ullrich Congenital Muscular Dystrophy	21	F	Interview	Email	Heterosexual	Congenital
21	Harjit	African	Physical	Non-progressive Muscular Dystrophy	23	M	Interview	In Person	Heterosexual	Congenital

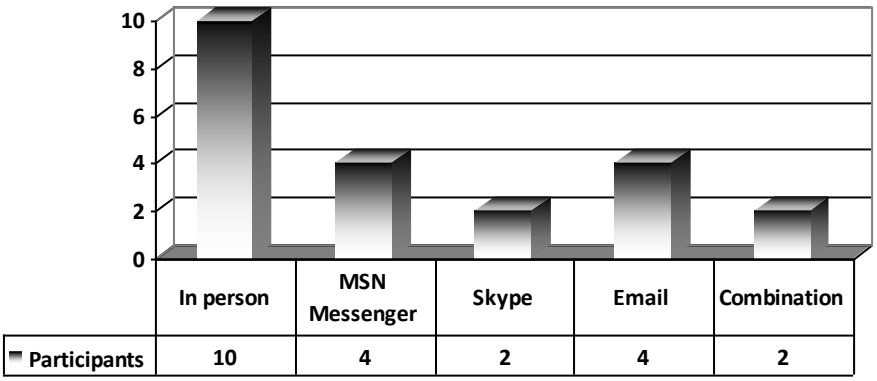
22	Helen	White-British	Physical	Limb Girdle Muscular Dystrophy	20	F	Interview	In Person	Heterosexual	Congenital (onset 7 years)
23	Jane	White-British	Physical	Charcot-Marie Tooth Disease	21	F	Both	MSN	Heterosexual	Congenital (onset 10 years)
24	Tony	White-British	Physical	Becker Muscular Dystrophy	26	M	Interview	MSN	Heterosexual	Congenital
25	Terry	White-British	Physical	Spinal Muscular Atrophy Type 2	20	M	Interview	Skype	Heterosexual	Congenital
26	Oliver	White-British	Physical	FacioScapuloHumeral Muscular Dystrophy	38	M	Journal	N/A	Heterosexual	Congenital (onset 11 years)

Data Collection and Analysis

Data Collection

A narrative approach was taken to the collection and analysis of data. The emphasis of data collection was eliciting participants' sexual stories which could later be subjected to a thematic analysis. In total, 27 sexual stories were collected, though only 26 were analysed (discussed later). In keeping with the research model, data was collected through semi-structured interviews and participant 'journals', defined below, both of which were offered in multiple formats ensuring that participants could voice their sexual stories in a format which suited their abilities and/or preferences (see chart 1). Although participant journals were designed to be flexible in format, these were received only in written form. In total, 5 participants told their sexual story via keeping a journal and 22 took part in a semi-structured interview. One participant was interviewed twice because having lost his virginity during the field work period he got back in touch and said he felt his sexual story had changed considerably and wanted his recent experiences to be included in his story.

Chart 1: Participant interview format choices (n = 22)



Multi-format Narrative Interviewing

In order to elicit participant stories, following some opening questions around disability identity and body image, topics were chronologically ordered (for example, covering childhood, puberty, and adulthood) in turn which was very effective at gaining sexual narratives. The original interview schedule (see appendix 10) consisted of asking questions about topics such as body identity and imagery, childhood, puberty and adolescence, previous and current relationships, formal and informal caring and support, finding partner/s, and sex. The narrative interview was semi-structured, meaning the schedule acted merely as a guide from which participant stories could deviate freely. Following a request for a non-disabled partner and a disabled participant to be interviewed together, an interview schedule based on the original was adapted to incorporate a partner's perspective (see appendix 11). The original interview schedule also underwent revision shortly into the field work after it was found that similar topics were coming out in participants' narratives which had not been included on the original schedule; for example the use of forms of sex work (see appendix 12). Sex work was referred to in the original schedule, but only in establishing whether a participant had or had not used a sex worker, and so the revision incorporated many more questions around such experiences.

Interviews carried out in person took place at participant's homes or at a local venue of their choice. Participants often requested more privacy than a conventional public social space (e.g. a coffee bar) would permit and so in such circumstances a local accessible meeting room was booked (e.g. within a community centre). Interviews lasted from 1-3 hours and were usually completed in one session. Video

messaging interviews (Skype) enabled this time to be easily shared over two or more sessions, and thus were useful where people experienced tiredness and fatigue. Instant messaging interviews took between approximately 2 – 7 hours. Frequently this time was divided into 2 or 3 separate sessions, chosen by participants to fit around both their schedules and their ability to type for a certain amount of time. Predominantly, this format was chosen by people aged under 30 years. Interviews which took place via email usually lasted for a few months, again, with participants deciding the pace of the interview and requesting further questions periodically.

Keeping a Journal: Writing Sexual Stories

The proposal to facilitate participants' writing of their own sexual story originated out of Research Advisory Group discussions about the power relations in research. The group concluded that reducing power imbalances between the researcher and the researched was central to constructing a more empowering process. Group members' concerns centred upon the presence and authority of the researcher voice in an interviewing context; they deemed it a hierarchical relationship whereby interviewee voices could be subservient. The group proposed that offering a less structured format which could be undertaken according to participants' own speed and time would offer participants' greater control of the process. Therefore it was suggested that devising a research method which 'removed' the researcher (as far as possible) could increase participants' feelings of empowerment through enabling them to have a more active voice (Janesick 1998).

Following such discussions the idea of participants writing what I call a 'journal' was piloted by Lucille, my pseudonym for a severely disabled spinal cord injured woman who wanted to take part in the research without her husband or a

personal assistant acting as a facilitator (which she didn't want). After some brief work to get started, Lucille kept the journal over a period of four months, writing whenever she felt like it. Upon completion Lucille took part in a feedback interview via instant messaging which gave me valuable insight into how to make the process of journal writing easier for future participants. Lucille, who had taken part in research interviews before, suggested that journal writing offered more of a personal insight into her feelings than an interview context did. She advised that the journal process could be emotionally taxing, but at the same time 'liberating' and that it would be useful to let following journal writers know that the process of journal writing could be tumultuous. Lucille said she liked that keeping a journal because it offered more time than a conventional interview and allowed reflection of how aspects of her everyday life (e.g. a trip to the gym) were shaped by her feelings about sexuality and gender:

> **Lucille:** *"Once I had decided how best to go about conveying my thoughts in a way which was not too abstract it became quite easy. I took an episode from a day which had raised issues relating to sex/disability and based my monologue around that!"* (For participant details, see pgs 96-98)

She also said the extra 'space' she had within the journal offered the opportunity to consider things from different perspectives: *"depending on mood, the physical task of writing the journal was a trigger for further discussion in my own head for the rest of the day or with others in following days".* However, Lucille also suggested that she had particular concerns about committing her experiences to paper, particularly regarding the privacy of people in her life (e.g. her husband). Adams

(2008: 184, emphasis added) states that 'the stories we tell *always* implicate others'. Thus as we construct stories and introduce characters (people from our lives), others are unavoidably drawn in to storytelling, regardless of the means through which the story is told. She also suggested that the keeping of a journal should, ideally, be followed up with a closing interview or debriefing session whereby both the researcher and participant have an opportunity to clarify or elaborate upon its content.

Lucille's participation in the pilot shaped the process considerably. In total, 4 other participants went on to write a journal, meaning it had a relatively low uptake rate of 19% of participants. Three of these participants continued with the process until they decided their journal was finished, and one switched to an instant messaging interview half way through her journal due to the project clashing with her undergraduate studies. More women (n=4) than men (n=1) chose to write a journal. This may have been because 'journal writing' is seen as a more feminine genre in literary studies, or that the (heterosexual) female participants had less incentive to meet in person. Of these participants, all said that the keeping the journal had been a positive experience. One participant, Grace, used the journal to work through a very recent catastrophic life event (her partner having a stroke) and to reflect upon her own feelings about sexuality and relationships as a Deaf woman. She enjoyed the experience and found it cathartic:

> **Grace:** "*I love writing. I really believe that writing helped to save my sanity at a very difficult time in my life many years ago. The journal method suited me down to the ground. Also, the anonymity was a key issue. It enabled me to be absolutely honest and frank. I think I would*

have been much less forthcoming in a face-to-face interview. As well as this, it's an access issue for me. Although I lip-read very well, there is always the possibility that if I attended an interview I might have some difficulty understanding. It gave me privacy which was important, as well as flexibility. Apart from the privacy aspect I think I would have found it difficult to find time to attend a 1:1 interview. I would not have felt comfortable doing instant messaging; I do not type accurately enough and I would have felt pressured to give quick replies. I liked spending time thinking about my responses and being able to look back and correct things before sending them in. I could not have done an interview over telephone because of my deafness - and I would not have liked to do an interview of this kind via Typetalk [a text to voice relay service for Deaf and hard of hearing people whereby messages are 'read' out to the non-Deaf receiver by a Typetalk operator, thus it is not private]. The journal method was perfect for me. I felt very much at home with writing the journal. I did feel a bit nervous at times as the subject is very personal. But at the same time I liked being able to be honest and open in a way that I cannot normally be. Sometimes it felt like a release in a way. I had to be in the right frame of mind and that was not always easy. However, it was always the case that once I had started writing, I was glad to be doing it! I did feel that I was able to shed some of the burden of events and feelings through writing the journal."

While this method meant that participants had the chance to censor their stories, possibly providing a more unnatural narrative flow, as Grace's account shows the

inaccessibility of other methods would have excluded her from participating. Interestingly, for Grace, journal writing was also a means through which she worked through a recent discovery that her partner had been having an affair. Grace used her journal to construct the romanticised story she wanted to tell (praising her partner considerably throughout the story) until, in her final entry, 'confessing' that she knew of his infidelity. This confession was more significant to Grace because she had made the decision not to tell her partner she knew of his infidelity; thus the journal was the only space in which she 'confessed':

> **Grace:** *"I was watching myself struggling to decide whether the betrayal should be included or not. I preferred the story without - but to have excluded the final part would have felt like dishonesty, even though you were at all times clear that I should include only as much as I wanted. That was a big struggle for me, and it surprised me. I'm glad I was fully honest though, otherwise what would have been the point?"*

Grace's account shows how much storytelling is a conscious process whereby a preferred reality can be constructed. It also shows how 'confessionality is an integral part of keeping a diary' (Jokinen 2004: 356). Thus, the time to reflect and the personal process of 'opening up' allowed Grace to provide a more intimate, 'honest' and accurate sexual story. In addition, her feelings about her partner's infidelity were very much tied up with her body image, disability identity, and (abusive) sexual past, thus contextualising the experiences she had previously spoken of throughout her journal. While any data collection method has both positive and negative characteristics, keeping a journal enabled exercising more control over story content, construction, structure, and order, meaning participants had a greater sense of both

power and ownership of the data they produced. It also, as Janesick (1999: 505) suggests, became a space to 'refine ideas, beliefs, and their own responses to the research in progress' which was of benefit to the research. From a researcher-perspective, participants as architects of their stories offered different types of stories to emerge which created a diverse and varied data set.

Data Analysis

In preparing for thematic coding and analysis, all face-to-face and Skype interviews were transcribed verbatim, inclusive of conversational features such as verbal tics, abbreviations, pauses and repetitions (Arksley and Knight 1999: 146). Transcripts produced through instant messaging and email were 'cut and pasted' into Microsoft Word documents but otherwise kept in the format in which they were produced and as intended by the authors. Data was initially coded into broad thematic categories using a computer assisted qualitative data analysis package (QSR*Nvivo). This was executed through repeatedly rereading transcripts to enable concepts and categories to be identified in raw storied data. Such themes were defined through participants' repetitions of particular topics (Ryan and Bernard 2003), thus making links across and between individual stories. While QSR Nvivo usefully facilitated the decontextualising and recontextualising of data and made coding and retrieval a more efficient process (Bryman 2004), once codes were identified and organised into broad themes, further analysis to find theoretical links was conducted manually. This stage involved enabling theories and patterns within thematic codes to emerge through manual colour-coding and through conceptual diagrams of more specific sub-themes.

Gibson and Somers (1993: 2) state that 'narrative is an ontological condition of social life'; thus 'humans are storytelling organisms who, individually and socially, lead storied lives; thus, the study of narrative is the study of the ways humans experience the world' (Connelly and Clandinin 1990: 2). My narrative approach, fitting with attempts to balance power relationships between myself and participants, considered stories to be co-constructions between the teller and the listener (see ethics section); thus I was implicated in participants' stories. Participant stories were (re)constructions of their lived experiences and subjective realities, as Bryman (2008: 553) suggests,

> 'The connections in peoples' accounts of past, present, and future events and states of affairs, peoples' sense of their place within those events and states of affairs, the stories they generate about them, and the significance of context for the unfolding of events and peoples' sense of their role within them.'

Therefore, storytelling was a way for participants to contextualise their lived experiences and present their subjective truth of reality. Thus, reality was not presumed to be singular, fixed or objective; rather participants' 'reality' was depicted and portrayed, meaning that the identities they projected were shifting and variable.

Stories were not treated uncritically (see Bury 2001). Reissman (2001: 12) states that when story-telling, 'informants do not "reveal" an essential self as much as they perform a preferred self, selected from the multiplicity of selves that individuals switch between as they go about their lives'. This does not mean, however, that a focus on performance suggests 'that identities are inauthentic, only that they are situated and accomplished within social interaction' (Reissman 2001:

1). Thus, as well as the content of stories, the purposes and motivations of stories were also considered. I considered that through (narrative) performance (Reissman 2003) participants (re)created and shaped their sexual selves and other identities (Bruner 1986). For example, some men and women used their stories to *sexualise* their culturally-ascribed desexualised identities and bodies, and construct (largely, hegemonic) gender identities through enacting and performing gender. Thus, to some extent, I gave credence to the performative aspects of narrative, what Reissman (2003: 23) calls, 'the 'displays' of self and identity that are not only spoken but also enacted and embodied, actions that offer insight into a preferred way of being'. However, different story chapters offered diverse types of performance; for example stories could be used to 'do things', they were *functional* for the teller (Coffey and Atkinson 1996). A good example of this is how some men *desexualised* their performances in their sex work stories, presumably for fear of (moral) judgement by myself and the wider audience and as part of managing the 'social deviancy' of purchasing sex.

Ethical Considerations and Reflexivity

This section will set out the ethical considerations which arose within the research while providing a reflexive account of my embodiment as a white, middle class, young, disabled female researcher carrying out disability and sexuality research. The role of researcher, once absent from view, now occupies a more explicit position within the research process. Bennet deMarrais (1998: xi) states that researchers now want to show 'the real story behind the finished product'. Good examples are Throsby and Gimlin's (2009) discussion of critiquing 'thinness' whilst wanting to be thin themselves, and Shakespeare's (1997) discussion of being a

disabled gay man and researching sex and disability. Therefore, offering a reflexive account of the process also provides the means to flesh out and unpack many of the tensions, contradictions and politics inherent within research. Thus, as Barton (2005: 319) suggests, 'demystifying the research activity' works as a 'means of documenting and examining the complex, contentious and contradictory nature of such work'.

Such reflexivity is also important to my role as an interlocutor of participants' stories. Adams (2008: 18) argues that 'we must reflexively probe ourselves to consider how our expectations of, and ethical stances toward, a story may alter its crafting and reception', thus the ethics of narrative, of hearing, interpreting and retelling stories will also be discussed. Following ethical approval from The University of Warwick Humanities and Social Sciences Research Ethics Committee (HSSREC) and adhering to both the British Sociological Association's (BSA) Statement of Ethical Practice and the Economic and Social Science Research Council's (ESRC) Research Ethics Framework, primary ethical concerns centred largely upon protecting participants from harm and invasion of privacy. Importantly, both of these ethical concerns of sociologists have parallels within disabled peoples' past and present social histories whereby they are routinely harmed and denied privacy through oppressive social and cultural practices (Sandahl 2003). Thus, it was crucial to assure disabled participants of the ethical practices upheld within the research process. This section of the chapter will work chronologically through these ethical considerations while offering a reflexive account of conducting research of this kind.

Researcher Declaration and Recruitment

Following initial enquiry, all participants were offered information on withdrawal, confidentiality, anonymity, the ways in which data would be stored and used, and informed consent was gained (see Adams 2006). For example, participants were reassured that they could withdraw at any time during the process (and that all corresponding data would be destroyed), that both anonymity and confidentiality would be both respected and upheld as far as possible, and that anonymity would be protected through using pseudonyms and the removal of possible identifying details (e.g. places, employers) throughout the research write-up and within stored data. However, participants were also notified that absolute anonymity could never be guaranteed and that there remained a chance, however remote, that they may be identifiable by another person in research write-ups. In order to minimise this participants were given the option to read through research transcripts and edit accordingly. Only one participant requested this and it was only to ensure I had anonymised specific details which he was concerned might identify him.

As stated earlier, I declared my status as a disabled person (and named my impairment) on all advertising literature and information sent to prospective participants. Non-disabled researchers conducting research on disabled people has a politically contentious history within disability research (Tregaskis and Goodley 2005; Priestly and Stone 1996; see also Branfield 1998), resulting in calls to 'give disabled researchers a chance' (Oliver and Barnes 1997: 881). Awareness of the political context of modern disability movements meant that I knew that declaring my disability was likely to be a fruitful position to take. Being a disabled researcher undeniably facilitated access to participants and thus yielded information I would not

have otherwise acquired. However, it also brought sizeable ethical considerations. For example, a participant may have assumed that I have a more embodied understanding of the issues faced or shared their experiences, or that I was more trustworthy, ethical, or aligned to disability politics than other professional gatekeepers in their lives. Many participants stated they would not have taken part in the research at all, or shared as much, had I been non-disabled, suggesting that a researcher's embodiment is ever-present within the research context (Reich 2003). In terms of recruitment it was found that my impairment, Congenital Muscular Dystrophy, could be misunderstood by participants with regards to severity. 'Muscular Dystrophy' refers to a wide variety of conditions which are characterised by a degeneration of muscle in the body over time. Forms of the condition differ in terms of speed of progression, severity, particular muscles, time of onset, and trajectory; many types are life limiting or shortening, though some are not. The substantial heterogeneity of the condition is often misunderstood through its popularised cultural understanding as severe, progressive and 'life-threatening'. Thus, participants (particularly those with more severe forms of muscular dystrophy and other muscle-wasting conditions) sometimes thought I had a more severe impairment than in reality. Thus, my own embodiment (and physical body) were an unavoidable part of the field work and had consequences for the research (see Warren and Hackney 2000).

Telling Sexual Stories: Possible Harms

The means through which to protect participants from harm are long-debated within social research (Warwick 1982). Harm can refer to a range of practices: 'physical harm, harm to participants' development, loss of self-esteem, and stress'

(Bryman 2008: 118). Due to the sexualities of disabled people remaining a relatively controversial topic and, as Shakespeare (1997) suggests, the possibility of disabled people lacking the language through which to talk about issues of sex and love, it was imperative to foster an environment which was sensitive and supportive and thus which minimised participants' likelihood of experiencing psychological harm or distress. In order to minimise harm, access to post-participation counselling with a counsellor who specialises in counselling disabled clients and who was familiar with the aims and content of the research was offered to all participants both throughout and following participation. However, while participants vocally appreciated this, none expressed the need for post-participation counselling.

It was not uncommon that the interview setting was the first space in which some participants had ever talked about issues such as sex and love with another person. Participants had often been ridiculed, humiliated or chastised when raising such topics within their own familial and social networks. This, inevitably, brought significant responsibility when managing participation in a way which would not quash the confidence and bravery it took to participate. Many participated because they acknowledged the silence around disabled sexualities as an issue (in both mainstream culture and disability movements). Others felt taking part may be cathartic, allowing them space to work on/through their concerns and anxieties around sexual and gender identity. The intimate nature of the research topic, combined with the sense of speaking about sex and love without fear or judgement, created some strong researcher/participant relationships. In addition, the extensive work it took to ensure participants made it to the interview (for example, regular conversations about access, participants' outlining their life stories in order to

determine ‘eligibility’ and the regular reassurance and contact required) meant that these relationships could already be developed prior to participation. At times such relationships became ethically complex to manage; for example, in order to protect participants I had to maintain a ‘professional distance’ (Fetterman 1991: 94) while at the same time constructing a supportive environment conducive to eliciting intimate experiences. This could be further complicated for participants who experienced considerable social isolation in their lives; for example, a couple of participants became quite dependent on the research relationship as a means of contact with another person which again highlighted the ethical circumstances of facilitating this relationship (for the elicitation of data), and more importantly, how to end it without causing considerable harm.

My identity as a woman could further complicate this process. For example, some male participants confused the open, supportive and gentle context of the interview and pre-participation contact with romantic or sexual feelings. Some men openly flirted throughout the interview (possibly enacting a sexualised and gendered identity they couldn’t perform elsewhere) and while sometimes this was in the context of asking questions about my own sexuality or sexual life, other times it was far more overt. Additionally, from another perspective, one male participant changed his participation method from an interview in person to an email interview because, he said, meeting me in a public place would relive bad memories whereby he had arranged to meet prospective partners who had either not turned up or left after seeing him. Thus, my gender identity was imbricated within research relationships as well as in participant stories. In addition, four male participants asked to meet again in a social context following participation. This created a predicament whereby I had

to decline such an offer without affecting the self-esteem of the male participant. On occasions where a participant wouldn't accept professionalism and the boundaries of the researcher/researched relationship as a valid reason for not making social contact outside of the research, I felt compelled to use my own relationship status as a means by which to decline, simultaneously offering details of my own private life. At other times participants (who were later excluded) could be sexually explicit, objectifying and sometimes frightening (see Peng 2007). For example, one participant was withdrawn from the research following participation because of his highly inappropriate conduct both during and after the interview, and another was withdrawn prior to participation, also for inappropriate behaviour.

Arundell (1997) problematises the research relationships between female researchers and male subjects, considering the complex power dynamics which can take place. Drawing upon her own research on divorced fathers, Arundell (1997: 364-365) found that male participants 'actively reasserted the conventional gender hierarchy as they told about their divorce experiences' and thus she concludes 'that the norms of the situation of the research interview did not override or displace those of a gender stratified society; gender work was ever present and predominant'. Similarly, some male participants in my research did not abstain from performing typical heterosexual scripts, regardless of assumptions about conventional power relations present within the research context. Likewise, my age and social class influenced the power dynamics of the research relationship with some participants; for example, one older participant said he initially felt very uncomfortable talking about sex to a woman "*his daughter's age*". In this case my identity contributed further to his existing feelings of inappropriateness surrounding his sexuality.

Similarly, my interviews with highly educated participants (who often knew about the historical, political and theoretical context of disablement) could instigate very different discussions about sexuality than those with less educated participants. Therefore aspects of my own gendered, classed, and disabled identity played a central role within participants' story creation.

Hearing and Co-creating Sexual Stories and Privacy Concerns

Nowhere was my subjectivity as a disabled person more important than in my role as an interlocutor and co-constructor of participant stories. I did not oscillate between these separate roles of interlocutor and disabled person; they were tangled and mutually dependent upon one another. Reissman (2003: 5) states that 'investigator positioning is important because it shapes the production of knowledge'. Participants' voices and stories, I propose, are never free from the researcher's interpretation (See LeCompte 1993; Blumenreich 2004), making the ethics of narrative crucial (Adams 2008). My (re)telling of participants' stories, which took place through analysis and subsequent write-ups, was as faithful, accurate and honest as I could possibly make it. Disabled people have long been misrepresented in research, and, according to Kitchin (2000), not only remain in fear of it, but their fear constitutes a primary reason for their overall dissatisfaction with social research. Such relations also contribute significantly to the friction that has subsisted between disabled academics and disability rights movements (Shakespeare 1996). However, my hope is that by undertaking the privileged position of re-telling stories I have made them more accessible, both to the research audience and other disabled people. As Blumenreich (2004: 80) states on representing the stories of children with HIV through his work:

> ‘Thus, by including my interpretations and descriptions of my relationships with the children, and by adding contextual information to make a child’s story more comprehensible or sharing background information unknown to the child him/herself, I believe I provide a richer story for the reader. This narrative technique may help the reader to more fully appreciate the child’s individual experiences than simply sharing the child’s words. This is not to claim, however, that my account is final or complete – only that it aspires to provide a complex representation.

Therefore, my voice as an interpreter does not, I hope, have the effect of disrupting, distorting, or removing stories from their subjective reality but is intended to assist in them being heard and understood. The politics of telling disabled stories is something I have considered repeatedly. Shakespeare (1996: 117) suggests that ‘disabled academics are subject to at least two monitoring processes: academic colleagues and movement comrades’. However, Shakespeare (1996: 117) manages to take a ‘hard line’ in his approach, suggesting that his academic perspective offers the ‘chance to consider issues which may have been overlooked in the heat of political debates’. Thus, he is clear that while he supports disability movements, he is not obligated to stay loyal to them (Shakespeare 1996). Representing certain types of stories and the ways in which they might be received by disability communities and movements was an ongoing ethical dilemma. For example, revealing disabled men’s sex work stories could be argued to legitimate oppressive conceptualisations of disabled sexualities as deviant. Simultaneously, presenting the abuses disabled people experienced throughout their intimate relationships may contribute to the harmful discourses of ’vulnerability’ which plague disabled people, and which are

not only disempowering, but dangerous (Waxman-Fiducca 1991; Hollomotz 2010). However, while my research findings may not be embraced by the political pursuits of wider disability communities, they do faithfully reflect, as far as possible, the lived and embodied experiences of disabled participants which are (unquestionably), of equal importance to me as a researcher.

Research 'on' disabled people has been labelled voyeuristic, and such critiques are, rather misguidedly, aimed only at non-disabled researchers (see Bury 2001). Disabled scholar Shakespeare (1997: 177-178) has highlighted how researching disabled peoples' sexual lives offers the potential for such narratives to be used and abused by 'unscrupulous readers [who] might find the description of disabled sex titillating'. He asserts that while it is important 'to capture the creativity and energy of disabled people's sexual expression', omitted within much disability and sexuality research (Shuttleworth 2010; Tepper 2000), that 'doing so runs the risk of supplying non-disabled voyeurs with material for erotic fantasies (not a usual danger of academic writing)' (Shakespeare 1997: 177-178). Shakespeare (1997) offers a coherent review of the ways in which his disabled research participants talked about sex. He maintains that disabled peoples' sexual stories were bound by the social context of disability: that disabled people lack the language through which to discuss sex, and that the disability community has failed to discuss private issues (Shakespeare 1997). The social context of disability inevitably impacted upon participants' willingness to narrate their sexual desires, experiences, and selves within this research.

Ethically, I found interviewing people about sexuality and intimacy often felt voyeuristic and intrusive. This was despite the fact that participants had provided

informed consent and had (brief) foreknowledge of the topics to be raised within the interview. There was a difficult line between eliciting the required data by encouraging disabled people to speak about certain aspects of their sexual lives, and subjecting their identities to the lack of privacy experienced throughout public life and thus serving to objectify their sexual behaviours and desires. These issues remain a concern even as I write up my findings. A way to work through this ethical dilemma is to acknowledge that by including the bodily (messy and fleshy) and the often 'uncomfortable' (Shuttleworth 2010: 1) aspects of disabled peoples' sexualities, the research is contributing to existing research whereby disabled peoples' sexual creativity, expression, and opportunities have been overlooked (Shuttleworth 2010).

Emotional Work

Dickson-Smith et al (2009: 61) suggest that 'undertaking qualitative research is an embodied experience and that researchers may be emotionally affected by the work that they do'. They also state that this 'emotional work' (Hochschild 1983) is rarely theoretically or empirically investigated (Dickson-Smith et al 2009). Listening to the stories of others, through which tales of isolation, loneliness, self hatred, abuse, and great sadness were not uncommon, was often difficult. Many of the stories told were ones of pride, self-confidence, resistance, and personal strength. However, many others embodied the oppression, discrimination, and prejudice many disabled people face as part of their daily lives. My own biography and subjectivity was complicit in my emotional work. Often my own lived experiences could be echoed in the stories of participants, particularly those with whom I strongly associated, for example, the stories of disabled women.

In addition, for some participants, taking part in the research and 'speaking out' about their experiences was part of a wider narrative of emancipation in other areas of their lives. 'Taking part' had much more significant and personal connotations than simply participating for sake of contributing to research. Participants often said that their participation was a catalyst for other changes in their lives. For example, one participant found writing her story a cathartic activity which allowed her to explore parts of her life she had shut down after her injury. On our last contact, she told me that telling her story had empowered her in ways she hadn't imagined possible; for example, she wore a skirt for the first time since her accident (10 years earlier) because she "*finally felt comfortable as a disabled woman*". Similarly, another got back in touch after taking part to tell me that talking about his situation had invigorated him to change the aspects of his life with which he had not been happy: he had felt dominated by his overbearing parents who he said controlled his life and did not allow him privacy. He reported that expressing his thoughts, ideas, and feelings in the interview gave him the strength to take control of his own finances and set new boundaries with his parents. While I take no credit for these acts of considerable determination and courage, at the time they were experienced as very real (emotional) connections which took considerable personal emotional management. Such intimacies were inevitable by-products of carrying out research of this kind.

Another significant form of emotional work I experienced was managing the sexist, disablist, and racist language and beliefs which could be a part of participants' stories. Problematically, due to the need to elicit data, these were prejudices to which I couldn't react or object. Discussions about sex work with male participants could

be very challenging to my own feminism, particularly hearing about certain sexual acts one male participant (who was later withdrawn) said he had carried out with sex workers, which I identified as abusive, humiliating, and demeaning (see O'Connell Davidson 1998). It was also troublesome hearing some disabled men's opinions on disabled and/or fat women, who were positioned as objects of disgust. However, possibly the most distressing aspect of listening to stories was hearing the extent of participants' internalised oppression and experiencing of psycho-emotional disablism (Reeve 2002). For example, some participants (and a research advisory group member) said that although they respected my efforts, politicising disabled peoples' oppression was meaningless because disability is a biological, natural and genetic inferiority of which social oppression is both justified and inherent to human nature (see Campbell 2009). A further sadness came from speaking to both young and older disabled people, who despite being part of separate generations, experienced similar disabling environments and prejudices – particularly with regards to sexuality and relationships. Another difficulty was acknowledging both the silence around and experiences of motherhood for many disabled women in the research (see Kent 2002; O'Toole 2002; Marris 1996; Mason 1992). Just three of the nine disabled women who participated were mothers and each of these women told stories of the discrimination and prejudice to which they were subjected by strangers, medical professionals, family planning clinics, and friends and family members. Female participants without children either quickly changed the subject when the topic of motherhood arose, or categorically stated that their experiences of both impairment and disability heavily contributed to their decision not to become mothers (see Thomas 1997). These experiences, I propose, highlight that

motherhood remains an area of social life through which disabled women are at best excluded and at worst abused (Prilleltensky 2003).

Conclusion

This chapter has provided an overview of the epistemological, ontological and methodological aims and outcomes within my research. Through regular consultation with disabled people, the research process, I suggest, remained accessible and empowering to those who participated, ensuring that participants had greater choice, power, and agency than within conventional research strategies and methodologies. This chapter has also outlined data collection methods, analysis, and ended with an ethical and reflexive contribution which considered the welfare of participants alongside my own subjectivity as a researcher. My hope, then, is that this chapter has provided a suitable context and background for the analyses which follow.

The following discussions of findings comprise of four chapters analysing participants' sexual stories. They correspond to specific areas of thematic inquiry which emerged from storied data. The first of these chapters outlines participants' self-conceptualisations of their sexual subjectivities and their experiences of carving out a public sexual identity within an ableist sexual culture. In doing so, this chapter offers a useful background for subsequent data analysis chapters. Chapter five explores participants' experiences of intimate relationships as a social space whereby by particular tensions occurred which required considerable emotional and other forms of work to be carried out. Chapter six reveals participants' explorations of embodied and material sexual pleasures and the constructing of a sexual identity both 'inside' and 'outside' of heteronormativity. The final data chapter offers a more

specific focus looking at experiences of commercial and non-commercial facilitated sex and a consideration of how such practices are problematically embedded within conventional gendered ideologies of power, heteronormativity, and masculinity, which not only serve to define, exclude and marginalise the sexual desires of disabled women, but reaffirm and maintain discourses of heteronormative sexuality.

Chapter 4: Public Sexual Selves

Introduction

The sexual identity ascribed to the impaired body and disabled identity is characterised predominantly by its asexuality; as McCabe (2006: 104) argues, disabled people are 'viewed under a paternalistic prism and considered as child-like and in need of protection, totally void or unworthy of sexual drives and as a result their sexuality is a taboo issue' (see also Milligan and Neufeldt 2001). This chapter looks specifically at disabled participants' experiences of managing and negotiating a sexual identity in the public sphere. My interview schedule started by exploring the formation of a sexual self as a key issue, and within that, there were a number of recurrent concerns expressed by participants which centred on their public image and the ways in which their sexual selves were perceived by others.

In this chapter, I report what participants told me about their formation of a public sexual identity. My analysis showed that participants' concerns about an ascribed (a)sexual identity occurred within particular social spaces and processes; for example, through experiences of sex education and adolescent sexual cultures, through their routine experiences of lacking privacy and autonomy, and through their experiences of voyeurism in different social contexts. I explore these spaces with reference to the forms of management and negotiation disabled participants' carried out in order to carve out their desired public sexual self. I situate this analysis broadly within Plummer's concept of 'intimate citizenship' and question the ways in which disabled peoples' ascribed asexual identities contribute to their lack of rights to intimate citizenship.

Citizenship and Sexual Life

One way to characterise the context in which disabled peoples' sexual selves are formed and articulated is by the absence of what Plummer (2003) calls 'intimate citizenship'. For Plummer (2003), 'intimate citizenship' is different from 'sexual citizenship' (see Weeks 1998; Richardson 1996), a claim to rights that many sexual minorities are making, because it focuses on claims to rights of public and private intimacies which extend beyond the erotic and the sexual (see Smyth 2009). Intimate citizenship is defined as,

> 'The control (or not) over one's body, feelings, relationships: access (or not) to representations, relationships, public spaces, etc; and socially grounded choices (or not) about identities, gender experiences, erotic experiences' (Plummer 2003: 14).

Plummer (2003: 14) identifies multiple 'intimate zones': 'self, relationships, gender, sexuality, the family, the body, emotional life, the sense, identity, and spirituality'. This perspective on 'citizenship' is underscored by a convergence of the private and the public: 'in the late modern world, the personal invades the public and the public invades the personal' (Plummer 2003: 68; see also Reynolds 2010), and it is these eroding boundaries of private and public life which constitute a transformation of intimacy (Reynolds 2010).

While Plummer's (2003) primary concern is upon emerging and new forms of intimate rights and new theories of citizenship that legitimate them, in this chapter I problematise the absence of rights to intimate citizenship for disabled people. Such rights are seldom challenged despite the fact that 'disabled people experience sexual repression, possess little or no sexual autonomy, and tolerate institutional and legal

restrictions on their intimate contact' (Siebers 2008: 136); many also 'face restrictions, penalties, and coercion, and are denied access to important information, all in relation to their sexuality' (Wilkerson 2002: 41-42). Thus, I consider the relationship between the experience of occupying an asexual identity, which participants described as restrictive and required work to 'correct', and their lack of rights to intimate citizenship. I focus initially on what participants said in relation to their experiences of learning about sex through formal and informal means, and their experiences of adolescence, before examining the ways in which they said they lacked privacy and autonomy within spaces where they received personal care. In the final section of this chapter, I explore participants' experiences of non-disabled voyeurism in different social contexts.

'Learning' and 'Adolescent Expectations'

In Britain, sex education for (disabled and non-disabled) young people remains discretionary because, despite New Labour attempts to make Personal Sex and Relationship Education (PSRE) mandatory in all educational institutions by 2010, this – as yet – has not happened, and looks unlikely within the priorities of the Coalition government. Current (normatively gendered) knowledges around sex, particularly those surrounding young people (see Holland et al 1998), are distinctly problematic because they are characterised conflictingly by conservatism, morality, and 'cultural erotophobia', defined by Wilkerson (2002: 41) as,

> 'not merely a general taboo against open discussions of sexuality, and displays of sexual behaviour, but a very effective means of creating and maintaining social hierarchies, not only those of sexuality, but those of gender, race, class, age, and physical and mental ability'.

At the same time, these dominant knowledges are set against a background of 'overtly sexualised environments' consisting of 'sexualised images in advertisements and the media' (Wilkerson 2002: 40-41). Lees (2000: 3) argues that 'the relationship between education and the development of sexual identity is relevant to the issue of citizenship rights' because, as she proposes in relation to gender, the omission of 'how the double standard operates and how gender relations are constructed' from sex education ensures that schools 'maintain the heterosexist gender order which leads to bullying and the denial of citizenship rights' for women and LBGT communities (Lees 2000: 9). Thus, sex education and the will to claim for rights to intimate or sexual citizenship are tightly bound (Lees 2000).

Davies (2000: 181) states that disabled people are 'excluded from most of the dominant socialisation processes that help teach and prepare people for love, sex and intimacy'. Sex education has notoriously been denied to disabled people in the past (Shakespeare et al 1996), and for some disabled people this still remains the norm. Shakespeare et al (1996) and others (Garbutt 2010; Hollomotz 2010) argue that the denial of even the basic anatomical knowledge of reproduction to disabled young people remains tied to dominant notions of infantilisation. This is further exacerbated for people diagnosed with learning disabilities, who are assumed 'incapable of forming substantial life preferences, learning the skills necessary to negotiate sexual choices, or making meaningful decisions in general' (Wilkerson 2002: 43; see also Brown 1994). Thus, widespread oppressive constructions of disability continue to shape the extent to which young disabled people acquire knowledge about sex and sex-related topics such as contraception, sexual health, personal relationships emotion, and reproduction. This not only impacts upon sexual development and

contributes to disabled peoples' 'internalized oppression' (Shakespeare et al 1996: 40), a central form of psycho-emotional disablism (Reeve 2004), but is argued to make some disabled people more susceptible to sexual abuse (Gillespie-Sells, Hill and Robbins 1998).

Participants' learning about sex was through a variety of formal and informal means, such as sex education, playground jokes, innuendo within teenage friendship groups, the media, and through older siblings. Many said that matters of sex were seldom discussed at home, and some said this was because their parents considered it unnecessary knowledge for disabled children (Shakespeare et al 1996). However, while one could argue that the situation for parents of non-disabled young people is not significantly different (Solomon et al 2002), parents with disabled children can face 'complex challenges in understanding and addressing young peoples' needs' (Swain 1996: 58) regarding sexual life, which may exacerbate the problem. A few of my male participants said that they knew so little that upon entering puberty and ejaculating for the first time, they thought they had a serious illness and were going to die. Most participants said that formal sex education was unhelpful because it was offered 'too late' and that its focus was too biological, clinical or just too narrow (see Jackson 1999; Holland et al 1998; Corlyon & McGuire 1997), meaning it had little relevance to their lived experiences:

> **Grace:** *"We watched films on menstruation and reproduction. That was about it. I read women's magazines but they did not tell you much. Sex was not talked about at home. I really knew hardly anything. I was curious but ignorant!"*

Grace's account is typical of many other participant responses. However, one participant, Terry, a 20 year old wheelchair user who had been educated in mainstream schools, said he was removed from a conventional sex education lesson and put into a special session for disabled students. While he acknowledged that this attention to specialist knowledge was beneficial, and considered radical by the school, he withdrew from the class on the basis that his segregation would only affirm peers' assumptions about his (a)sexuality. Terry said that teaching all students together about the sexualities of *all* people would be far more radical. He said that, even within the special session (taught by a non-disabled person), there was little practical and informed advice on issues relating to the inter-relationship of impairment and sexual life:

> **Terry:** *'"Today we're going to learn how people with muscle weakness are going to put a condom on." I remember saying – "to be fair you're talking to someone who can't even open a chocolate wrapper, so I haven't got much hope, have I?" I remember it was almost like a shock because he [teacher] said "does that mean you're not going to use contraception?!" and I said "well no, obviously I'd just ask the other person to put the condom on..."'*

Terry's experience shows that even within educational spaces where disability-specific knowledges are offered, disabled peoples' learning about sex can remain defined by its deviation from dominant ableist sexual cultures and practices. For example, his teacher's (ableist) assumption that the only alternative to not being able to put a condom on independently is to practice unsafe sex offered Terry little creative resolution to this reality. Therefore, a focus on normative bodies and

normative bodily experiences alienated Terry in his sexual learning. The heteronormative sex education that he and other participants described serves, I suggest, to affirm the compulsory way in which sexual interactions take place, and, that the absence of impairment in this space – or as Plummer (2003: 14) asserts, the 'lack of representation' – confirms that heteronormative sexuality remains exclusive to non-impaired sexually 'able' bodies. This notion is supported by existing literature which argues that mainstream sex education continues to promulgate myths such as '"disability implies asexuality"' (Thompson, Bryson and DeCastell, 2001: 59) because young disabled people 'internalise and use language that reinforces the heteronormative dominant discourses relating to what constitutes "natural" and "normal"' (Blythe and Carson 2007: 37; see also Waxman-Fiduccia 2000; Gillespie-Sells et al 1998).

Learning about sexuality only through a heteronormative lens reinforced dominant expectations of adolescent sexuality for most congenitally disabled participants. Not meeting such expectations caused feelings of anxiety and failure (see Anderson and Clark 1982). This was often expressed in relation to feelings of failure in other areas of adolescent life, for example social life. The majority of congenitally disabled participants felt they had 'missed out' on much of the formative teenage experiences such as getting drunk, going to parties, and having fleeting sexual encounters because of issues with access, transport, and non-disabled peers' attitudes. Being ostracised from these key adolescent social spaces contributed to feelings of low self-worth and esteem and further exacerbated their frustration and isolation. Many said that prior to entering secondary education (as children) they'd had many friends; felt included within social networks, and were less aware of their

disability (see Tamm and Prellwitz 1999). These participants also said that, until this age, they had always presumed that they would have a normative heterosexual life: a sex life, getting married and having children. However, this expectation changed drastically during their time in secondary education where exclusion from adolescent social and sexual spaces confirmed their status as Other. For participants with neuromuscular conditions with pre-teen/teenage onsets, adolescence included a difficult negotiation of coming to terms with a newly acquired impairment and disabled identity at the same time as dealing with the typical tumult of teenage life and the formation of a sexual identity (see Galvin 2005). This was often highly conflicting, and the transition from non-disabled to a disabled identity was explicitly said to hinder social and sexual opportunities. For example, Helen said that her rapid accession to a wheelchair alienated her from her peers: "*Once you've passed that barrier you can't just... they've made up their minds and it's quite hard to come back from it*".

Many participants felt inadequate during adolescence because their sexual experience came later than those of non-disabled peers and in different forms (see Howland and Rintala 2001). For example, many did not experience penetrative sex during adolescence, often because of factors such as logistics, access, and a lack of privacy. Jane described herself as a 'slow starter' and said hearing friends' sexual stories made her feel left behind. Kadeem (and many others) thought sex was something unavailable and out of reach. Robert worried if he'd ever lose his virginity, and Rhona said that if she wasn't disabled she would have been "*sexually active at a much younger age*". She also said that she did "*get off with men in clubs*" but that the most important part of this was friends and peers seeing it take place, and

thus, "*that men were interested in me*". To perform the role of a desired woman in whom men were "*interested*" is to embody the highly gendered role of the seductress. Rhona's attempt to project a sexual identity to her peers was a practice carried out by other participants, the emphasis inevitably being upon affirming that a sexual identity is *possible* and that they could both desire others and be desired. Through these actions I propose that Rhona was (re)claiming a sexual self presumed non-existent; thus she sought to resist her desexualisation by managing her public sexual identity in this way. Participants explained that this sexualisation functioned to aid inclusion into prevailing adolescent sexual cultures.

Exclusion from adolescent cultures was described as a very difficult experience, as has been found in other research (see DeLoach et al. 1983; Morris 1993). Several of the severely disabled participants did not experience sexual relations in any form during adolescence. Sally, a 21 year old student, felt desperately frustrated about having not yet lost her virginity:

> **Sally:** *"Up until recently I never doubted I'd someday have sex, but now, I'm really not so sure. It depresses me that I might never have that experience. I really want to experience sex, I am 21 after all! Some of my friends have been doing it since they were 13! But, as I say, I just don't know how to make it happen, & I doubt it will ever happen. Who would want to have sex with me when there are plenty of normal girls more than willing?! Besides the fact, I am still stuck living with my bloody parents... wouldn't that be cosy."*

Sally's account highlights her low sexual self-esteem (*"who would have sex with me when there are normal girls willing?!"*) and the difficult transition period many

young disabled people experience between childhood and adulthood (Goodley and McLaughlin 2011). Difficulties in finding employment and organising accessible housing and personal care can often mean living with parents later than non-disabled peers – which Sally implies affects her ability to explore her sexuality. In addition, Special Educational Needs (SEN) transition planning for disabled young people, the final transition plan of which 'should draw together information in order to plan coherently for the young person's transition to adult life' (Special Education Needs Code of Practice, 2001: Para 9:51), often omits the social and sexual aspects of 'adult life' in favour concentrating upon independent living, further education, and employment. This means that issues which Sally claims were very important to her sense of personhood as an adult (e.g. sexual life and relationships) remain overlooked.

Participants' feelings of frustration about delayed sexual experiences could be worsened by having negative thoughts affirmed by family or friends, teachers, and peers. Reeve (2004: 91) suggests that trusted people within disabled peoples' own social networks such as family members and friends can be 'agents of psycho-emotional disablism', equally, as well as strangers. For example, many participants had experienced parents, wider family and peers telling them not 'to get their hopes up' regarding sexuality and relationships. This only served to reinforce ableist cultural messages about disabled sexual selfhood as being both inappropriate and improbable (Wilkerson 2002):

> **Kadeem:** "*Family members made comments like "we pray you get better so you can get married and have kids"... That broke my heart."*

> **Abram:** *"I remember one of them laughing at me and telling me "ha-ha you're never going to have sex" and I was like, "Oh I'll show you!" I still remember that... years later I was thinking 'he was a right wally, but I don't half feel that he's right now'... he was spot on, he was."*

Kadeem and Abram's experiences were not uncommon among participants. A few other participants confirmed that verbal bullying had targeted their presumed asexuality, reinforcing the perceived lack of a sexual self and sexual ability which positions disabled people as less than human (Siebers 2008) in a society which privileges sexual activity as a sign of adulthood and citizenship rights (Weeks 1998). Siebers (2008: 140) claims that notions of disabled people as less than human are rooted in assumptions about reproductive capacity, which 'marks sexuality as a privileged index of human ability' (see also Jackson 1999; Tepper 2000). Therefore, in having a body presumed incapable of sexuality and reproduction, Abram was considered of less value and thus worthy of abuse. This 'sexual bullying', according to Lees (2000: 4), 'is intricately connected to the way sexual identities are formed and maintained in the heterosexual gender order' and thus experiencing bullying of this kind during adolescence contributes to a later denial of (sexual) citizenship rights.

For some male participants, feelings of inadequacy and frustration surrounding feeling both socially and culturally asexualised were so severe that they contemplated suicide, showing the power of normative sexual markers of masculine sexuality and the extent to which not meeting them can be deeply oppressive:

Terry: *"I didn't think I was going to have sex, so it was quite an upsetting time, and there was a major point in adolescence where I did contemplate committing suicide because I didn't think I'd ever develop into an adult where I'd have all the experiences of non-disabled people."*

Abram: "*I never had any [sex] there [at university]; by the time I left university I almost topped myself".*

However, other male participants who were equally concerned about losing their virginity negotiated these feelings of inadequacy by visiting a sex worker during adolescence. Seven of sixteen male participants had used a sex worker, and for three of these it was their first experience of penetrative sex. Using a sex worker was understood by these participants as the *only* way they could gain *vital* sexual experience, and thus acted to resist their exclusion from normative adolescent sexualities. While men's use of sex workers is discussed in depth in chapter seven, it is important to note here that no female participants said they had used a sex worker. However, Sally told me in her email interview that she had considered it:

Sally: *"I have read about a few disabled lads in Target MD magazine [disability publication] (whenever I read or hear about muscular dystrophy they always seem to refer to boys with Duchenne MD - girls have MD too!!!) who have actually paid for sex because they didn't feel they'd ever get the experience otherwise. I have actually thought about doing this myself, not now because I live with my parents & if I did it's not something I'd tell ANYONE, but perhaps when I have my own place. Then again I think my self-confidence is so diminished I couldn't ever actually pay someone for sex because... I guess I'd feel ashamed,*

worthless, and I want respect, I want the person I have sex with to actually like me & be attracted to me."

Sally's account suggests that paying for sex is a highly gendered activity based on conventional ideas about male and female sexualities (Sanders 2008). It also indicates how the sexual stories of young disabled males (predominantly those with progressive/life shortening impairments) are generally privileged over those of young disabled women. This can, in turn, both normalise the use of sex workers in certain spaces within disability communities (Jeffreys 2008), yet also leave female sexualities unattended (Sanders 2010).

Lacking Privacy and Managing Voyeurism

Shakespeare (1996: 66) argues that 'disabled people face a considerable amount of curiosity and voyeurism'. While this is not wholly exclusive to disabled people or the impaired body; 'gay, lesbian, bisexual, queer and transgendered people also suffer from a lack of sexual privacy' (Siebers 2008: 138), many disabled people still reside in institutions and residential care homes with significant lack of autonomy and privacy combined with substantial surveillance (see Shue and Flores 2002). As Kaufman et al (2003: 8) state, 'the definition of privacy changes when you have no lock on the door, or when you request private time at a specific hour knowing that it will probably be written down in a log-book'. Wilkerson (2002: 34) problematises the lack of privacy within institutions, suggesting that,

> 'Sexuality is vital pleasure, interpersonal connection, personal efficacy, and acceptance of one's body and of self more generally, all goods which might be useful to disabled persons in nursing homes. Furthermore,

> because one's autonomy is already compromised by residing in a nursing home, the violation of both sexual agency and personal security imposed by this loss of privacy should be recognised as a serious harm.'

The routine desexualisation (and sometimes dehumanisation) of disabled people through residential care and nursing home settings constitutes a serious denial of (sexual) autonomy, agency, and control of their sexualities and relationships (Shakespeare et al 1996; Garbutt 2010). These factors are integral to the establishment of rights to intimate citizenship in current society (Richardson 2000). Much of the surveillance disabled people experience is based on the casting of disabled people as innocent, 'vulnerable' and in need of protection (Shakespeare et al 1996). Even for those who live in the community, privacy can still be an aspiration rather than a right. Paradoxically, as well as desexualisation, disabled sexualities are, at the same time as being prohibited or assumed absent, fetishised and considered 'inherently kinky, bizarre and exotic' (Kafer 2003: 85). They are, as Brown (1994: 125) says, assigned paradoxical social categories of 'asexual, oversexed, innocents, or perverts'. Ableist curiosity about disabled sexualities is rooted in Western discourses of sexuality as a fundamental part of adulthood. Thus, without a sexual identity one cannot 'claim a full subjectivity' (Shuttleworth 2002: 122). The 'asexual' identity therefore becomes an object of fascination and examination. This section will examine disabled participants' experiences of lacking privacy through care, and their experiences of managing the voyeurism of the non-disabled gaze (Reeve 2002) in relation to disabled peoples' lack of rights to intimate citizenship.

While no participants in my research resided permanently in a nursing home or residential institution (all now lived within the community), many had experienced

institutional living through, for example, regular respite care, long periods of hospitalisation (particularly those in rehabilitative spaces following spinal cord injury), and residential special education. Participants also lacked privacy generally within community-based caring arrangements and familial caring. Privacy – or rather a lack of it – was, therefore, a significant factor in shaping both participants' sexual expression and sexual self. Privacy was both disrupted and denied predominantly by parents, families, personal assistants, school nurses and teachers. Participants expressed what a lack of respect for privacy had upon their sexual selves:

> **Pete:** *"Because I need such personal care I have never been able to have a 'real' personal life - no real secrets."*
>
> **Shaun:** *"Before Hannah [wife] I had live-in carers, so you're never really by yourself... so that was really really tough."*

Pete's assertion that he has never been able to have a "*'real personal life"* shows the sizeable extent to which a lack of privacy can impact upon feelings of (sexual) autonomy. Additionally, to Shaun, never having lived alone contributed significantly to his inability to sexually explore both his own body and his sexual desires. Many older participants told painful stories about the ways privacy was denied during caring in adolescence:

> **Pete:** *"New carers I didn't like especially around puberty when my bits got bigger & the growth of hair, etc. I would be very uncomfortable with myself. I have always needed help washing and showering & dressing. I remember even crying as I didn't want to undress for bed in front of new helpers. I'd get in a right old state. I wouldn't even go to the toilet as I*

was so embarrassed. I wouldn't drink so I wouldn't need the toilet especially at night as the regular school nurses used to threaten to put you in an incontinence urinary sheath or in an incontinent pad. I wasn't incontinent but if you needed more than one wee in the night then using one of these things was discussed... At camp I'd ask for doors to be locked while I was being showering. It never was locked... the door was always wide open."

Pete's experiences show that a refutation of privacy is not only dehumanising, but harmful and frightening. Pete, now 42, reveals that he had to manage his body (not drinking to ensure he didn't need the toilet) in order to minimise the gaze and authority of the nurse. Younger participants were still living through such experiences at the time of interview and central to men's stories were erections, ejaculation and wet dreams. One participant, Harjit, who had moved to the UK from Africa to study, said his parents had insisted on accompanying him to continue in their role as his full-time carers. Harjit said that his parents were very overbearing and that, at 23 years old, he still shared a bedroom with them:

Harjit: *"My parents must know I masturbate but they've never really asked me and it's never really come up in discussion. I have had nights when they're having sex, but obviously I'm 'asleep' and facing the other side... it's just frustrating because it's like, I understand, fair enough, they don't get any time on their own, it's fine I'm not going to say anything... you just try and sleep and occupy your mind with something else, but it's just frustrating thinking 'well, why can't I? What's different with me?*"

Sleeping in the same room as one's parents is something that would *rarely* happen to a non-disabled person of Harjit's age. It not only shows that disabled sexualities remain very much a product of social environment (Taleporos and McCabe 2001), but highlights how much disabled people remain without agency and autonomy in non-Western cultures – particularly, where little state-funded care provision and high rates of poverty together with a cultural reluctance towards non-familial (paid-for) care can mean disabled people remain infantilised within both family and wider networks. Similarly, Abram, an Asian IT worker, revealed how he felt his privacy was severely compromised during early adulthood:

> **Abram:** *"I remember being a little bit embarrassed by... the fact my dad was doing all my caring... I used to get quite a lot of erections and ejaculate quite a lot during the night and I remember my dad mentioned it to my mum who thought it was a problem and [said] "Should we call the GP?" and it was like, "Mum, mum, it's...not a medical problem!"... It got me into a bit of trouble back in [residential school] as well, 'cos I remember one of my experiences was trying to ejaculate whilst getting washed [by an assistant] and I remember I got reported to the head of house by a couple of them [assistants] and getting called in first thing in the morning by the head of house. [...] I don't think it was that I was turned on by the caring; it was I sort of felt the need to ejaculate, erm, and that was just the only way. I think the urge was that it would be washed away and done and dusted. I felt pretty bad. I think that problem contributed to the feeling that somehow... my sexuality was not, I can't*

take it for granted as being a right of mine. I've carried that through all these years."

Abram's account reveals the constraints of having an impaired body which is looked after by parents or caring assistants. His account illustrates a lack of freedom to exercise his own (sexual) body and feelings, a fundamental requirement of intimate citizenship (Plummer 2003). His parents' potentially desexualised view of him cast his (normative) sexual expression into the realms of abnormality and thus defined it as problematic (and, tellingly, in need of medical attention). His story shows a direct link between this lack of privacy for sexual exploration of his own body and the problematic strategy of trying to find 'relief' via means that were not under the gaze of his parents. However, the only accessible means for this (ejaculating while being washed by a carer at school) involved taking the risk of making something that is usually private and seldom discussed a public matter. The public nature of his strategy simultaneously shifted his sexuality into a deviant space for which he was chastised. This shows for disabled people how the normative can become deviant. Such experiences were common for male participants, particularly when erections and ejaculation were 'accidental' during personal care:

Pete: *"At physiotherapy I used to get erections for no reason except for being stripped to my boxer-shorts... A young woman helper could see I wasn't happy. I explained to her I needed the toilet but couldn't undo my jeans. She said she would help. She pushed me in my wheelchair into the toilet, she undid my jeans. I could smell her perfume. I stood up to go wee and as I stood her hand went on my bare bottom. I thought maybe she was making sure I didn't fall over. While I was peeing she crouched down*

and said "have you finished?" I don't know why but I started to get aroused. Her perfume seemed to fill the air. As she started pulling my shorts back up she brushed my leg with the back of her hand as she did I got very, very aroused. I fell back into my wheelchair embarrassed. I was expecting her to get mad or to get a nurse. But she finished fastening my jeans...I could see my pants getting 'sticky'."

Pete's graphic account (which happened during his childhood 30 years earlier) shows the extent to which these fleeting feelings of inappropriateness, embarrassment and humiliation can remain. While such 'accidents' could be argued to be the 'natural' product of a young man's body being touched and intimately cared for (particularly during puberty), it is significant to note that no stories of such incidences involved male carers. This is not only because of the gendered and heterosexist nature of care work (and thus the centrality of the female worker body within care relationships), but may also have been because doing so was considered as potentially disruptive to male participants' heterosexual identity and performances. Similarly, no female participants talked about arousal during personal care; either because voicing such experiences risks shame or embarrassment (particularly for female sexualities), or because such experiences seldom occurred (see chapter 7).

Additionally, many participants spoke of their privacy impugned through the voyeurism of friends, family and peers, as well as of strangers; thus the majority of participants' sexual lives had been subjected to the non-disabled gaze (Reeve 2004). For example, most had experienced being 'asked' whether they 'could have sex':

Helen: *"When I was younger I remember this one guy at school said "Can you have sex?" I was like "Yeah!"... Getting people to see past the chair... it's difficult."*

Lucille: "*One thing that does annoy me is how people are curious about whether you have sex or not but they never actually ask (thankfully!!!). Friends of family or family ask other family but not me. Weird, I'm sure they don't ask their family or friends the same things about their non-disabled friends! I find it funny in a way."*

Terry: "*People have the opportunity to ask me when I teach, and probably about fifty percent of the questions are related to sex and relationships... I find it encouraging to have young people ask me about sexual relationships and disability because it encourages me that they want to find out more, really."*

Morris (1991: 29) argues that it is disabled peoples' physical differences that make their 'bodies public property' and thus which invites 'the total stranger or slight acquaintance coming up and asking us the most intimate things about our lives'. Reeve (2004) proposes that stares from non-disabled people (part of the non-disabled gaze) constitute an objectifying form of psycho-emotional disablism. While the collection of participant quotes above suggests that such inquiry is received with good faith, and for Terry, is a platform from which to educate people, for others it could be a point of frustration and a difficult social situation to negotiate. Shaun, a spinal cord injured wheelchair user, and his non-disabled wife Hannah, explained their difficulty:

Hannah: *"A lot of people [friends] will ask, "Does Shaun's willy work?" and I always say "Yes it does." I remember in the beginning Shaun would say, "Say it's none of their business" but I guess... I almost feel I have to prove that Shaun is a man."*

Shaun: *"And that really does make me angry because you wouldn't ask anybody else that, you 'know... so it's like why do these people think they've got the right to ask these kinds of questions? I know it's curiosity but..."*

Hannah: *"But I'd much rather say, "Yes it works" rather than "Don't ask", which is implying it doesn't."*

Shaun: *"But it does work.... most of the time..."*

Hannah: *"Yeah but I could also say "people mind their own business" but I've had difficulty. If you say "mind your own business" I think that people are assuming that you're impotent, that's how I feel."*

Shaun: *"But I just think you put the ball back in their court and ask "why are you asking me that question? You wouldn't ask me that question if I were going out with an able-bodied partner"..."*

Hannah: *"Yeah... it's almost that thing, well – you have to prove, prove that Shaun is a man..."*

Shaun: "*Just say "Yes! And it's enormous!" [Both laugh]"*

This dialogue from Shaun and Hannah, the only couple to be interviewed, shows how the management of curiosity into their sex lives (and bodies) can impact upon

their lives and their identity as a couple. Both want to resist such invasive voyeurism but manage this through different means. Hannah shows resistance through wanting to prove Shaun's masculinity and virility to others ("*you have to prove that Shaun is a man"*), while Shaun shows resistance through wanting to challenge curiosity and ignorance ("*why are you asking me that question?").* The account also illustrates how both the disabled person and their partner can share the burden of voyeurism. Terry voiced a similar experience whereby people would ask his girlfriend, as he put it, "*what's it like having sex with a disabled person?"* As Sakellariou (2006: 104) suggests, while any couple may face difficulties with sex, 'when one or both of the partners are disabled somehow an utterly private issue is transformed into a public one'. Sometimes voyeurism displayed real ignorance of disabled sexual subjectivities; for example, Terry said that friends assumed, as a disabled man, he only watched porn that featured disabled performers, and other participants commented that, when on a romantic date, people would assume their girlfriend was their sister. For Pete, (ignorant) voyeurism constituted a painful assault on his (as he described, already fragile) masculine identity:

> **Pete:** *"Well, I have been asked if my wife was my sister. I've been asked if my kids are really mine. I have been asked if my wife & I needed IVF to get our kids. And I have been asked if I needed Viagra. All these things are very much a punch in the gut to masculinity."*

Pete's account reveals that such voyeurism could be experienced as emasculating. Additionally, it shows how dominant constructions of disabled people as degendered and sexless contribute to their inability to be recognised as parents, or as having the ability to parent (see Thomas 1997). The fact Pete (and other participants)

experienced strangers assuming their romantic partners were friends or siblings shows that many disabled people are denied the privilege of 'public validation' of their intimate partnerships, a primary area where Richardson (1998) proclaims sexual citizenship should be acquired. Voyeurism was also found to increase in particular social contexts such as during adolescence and in adult social spaces. Terry talked about having to managing the burden of the non-disabled gaze while socialising in nightclubs:

> **Terry:** *"Erm, it's always women. In fact, it's never been a bloke; I think they've always asked a mate, they'd never ask me... But the women, they'll ask me to my face [about sex], and we'll have a laugh about it. You do get drunk people being very heavily patronising, they'll insist on buying you drinks etc, or they'll want to make you their best friend the whole night, erm, and that's part of them being drunk and perceiving your disability as a fate worse than death. Basically, they're either very inquisitive about sex, or they're patronising, or they're abusive, really."*

Disabled people regularly face discrimination, prejudice and abuse when in adult social spaces (Reeve 2002). As Morris (1991: 25) suggests, 'going out in public so often takes courage, it is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility'. Terry's account reinforces this and illustrates that in these particular social spaces and environments, disabled people must manage such reactions, either taking on the role of educator (educating non-disabled people about the lived realities of *being* disabled) or resisting patronising attitudes and abuse. However, Terry told how he perceived certain

instances of voyeurism to be grounded in sexual attraction and sexual desire for his impaired body:

> **Terry:** *"Well, I think some of them just want to know for their own benefit and then some of them will be interested in taking it further. They're either interested, or they've asked that question 'cause they want something to go on afterwards. I mean, I can imagine that some people have a fascination of having sex with a disabled person – there was one girl, for example, she said "well, my ambition is to try and sleep with as many different groups of people". So I joked, "have you had sex with lots of ethnic minorities?" she said "yeah, I've done a black person, a Chinese person" and I said "well, have you done a disabled person?" and she went "no, but they're on my list". So it's almost like, there are people who want that kind of experience that's very different – so, it's curiosity, you know, you do get a few people who–just find you attractive."*

Terry's account shows how he understands curiosity in this context, at least partially, as a source of fascination and titillation for non-disabled people regarding the ways in which his (impaired) body *performs* sexually. Thus rather than 'curiosity'/voyeurism maintaining the impaired body purely as a spectacle of abjection (see Adams 2001), the presence of an impaired body – as a challenge to heteronormativity and the 'compulsory able body' (McRuer 2006: 2) – invites non-disabled people to consider it as a site of sexual potentiality. As Terry's experiences demonstrate, this can be a transformative social space and a means of accessing sex where his impaired body becomes 'a locus of power' (Solvang 2007: 56), rather than

just a ‘fetishized object’ (Shakespeare et al 1996: 03; see also Solvang 2007; Waxman Fiduccia 1999; Hahn 1988).

Sex Talk

Talking about sex (‘sex talk’) both within wider social networks and particularly to medical professionals was something many participants found uncomfortable. As discussed in chapters one and two, the medicalisation of the impaired body means it is, at best, a site for cure and intervention (Hahn 1981; Milligan and Naudfeldt 2001; Tepper 1999, 2000). So pervasive is this medicalisation, argues Thomas (2002: 40), that the emergence of other models of disability (e.g. the social model) ‘have had little or no impact on constructions of disability in the heartlands of Western scientific medicine’. A medically managed impaired body inevitably has different priorities set out for it than a ‘healthy and able’ body, (of which sexuality is not one), because it is defined solely through deficit models (Tepper 1999, 2000; Milligan and Naudfeldt 2001). Wilkerson (2002: 34) states that medical discourse is ‘insidious in its ability to shape not merely our sexual options but a sense of ourselves as sexual beings, and ultimately our very identities for ourselves and others’. In this section I examine participants’ experiences of sex talk firstly with medical professionals and later in wider social networks. I conceptualise the conversation as a public space which, for some participants, required management in order to present or claim a sexual identity. According to my participants, their right ‘to choose how they organize their personal lives and claim identities’ (De Graeve 2010: 365), which is integral to intimate citizenship, was denied in sex talk with medical professionals and also in wider social networks.

Participants received variable responses from medical professionals when attempting to talk about sexuality, sex, and sexual and reproductive health. Often these matters were ignored within doctor-patient relationships despite participants raising and speaking out about particular issues of concern to them (see Mairs 1996). When participants did ask questions relating to sex, help and advice was not forthcoming. For example, Gemma told a story where she raised the issue of sexual pleasure (she had trouble orgasming because of an associated nerve condition) with a consultant:

> **Gemma:** *"And, he [consultant] was just totally embarrassed. I thought 'how bizarre', he just didn't want to tackle it at all. He was totally...aghast…didn't comment and carried on [laughs]… I think having a couple of lesbians discussing their orgasms was not what he had in mind [...] I just think that's quite telling, really."*

Such an unsupportive and unaccommodating reaction emphasises that impaired bodies which experience sexual dysfunction are seldom seen as problematic (Tepper 2001). By seeking advice from her consultant, Gemma was presenting her sexual identity, which was disavowed. Other participants avoided talking to medical professionals about such issues, doubting the help they could offer. Helen, a 20 year old mother with a progressive muscle condition, told how doctors were particularly brutal when she fell unexpectedly pregnant. The reproductive activities of disabled people are shrouded in biomedical dominance which positions them, should they choose to reproduce, as (socially and personally) irresponsible, incapable, and as dangerous risk-takers. Thomas (1997: 640) suggests that having children is particularly difficult for disabled women whose 'reproductive journeys are strewn

with social barriers of an attitudinal, ideological and material kind'. Helen said that her decision to keep her baby was treated with shock, and that her team of doctors consistently warned throughout her pregnancy that carrying a baby to full term meant she was "*going to die*":

> **Helen:** *"They [doctors] were awful, the lung doctor just told me... "You're going to die", which was just gruesome. I went back to see him a few months after I'd had him [her baby] and I was like 'ha!!'"*

While Helen could resist the medical dominance and control that blighted her pregnancy (a form of psycho-emotional disablism), she experienced doctors voicing concerns in this way as incredibly frightening. It indicates, as Thomas (1997: 636) notes, that while many women 'experience a sense of loss of control over their bodies during pregnancy and childbirth as doctors and other health professionals 'take over', this experience of loss of control can be intensified when 'disability' is an additional factor in the lay - professional encounter'.

However, a few participants said they had found helpful doctors. These views were usually expressed within stories about 'one special doctor' who had offered productive help and advice around sexualities, sexual health and relationships, suggesting that there are pockets of empowering support within the medical profession. For example, Kadeem said that his GP gave him time to talk through his worries about sexuality, had researched sex surrogacy services for him and had even applied to his local Primary Care Trust for funding of a sex surrogate (which was later rejected). Jenny, one of the few disabled women in the sample who became a mother, said that during her time in a spinal injury ward (where she resided from the ages of 11-14), and throughout her life, her consultant had been very supportive

regarding reproductive health, pregnancy, and sexuality. She credits this support for her being able, as a severely disabled woman, to have a baby at all, particularly in the context of 1970s Britain, when disabled peoples' civil rights were only just emerging.

Engaging in sex talk within wider social networks could be equally challenging. There were some participants who found they could talk about sex and their sexuality with ease (both within the research interview and in wider social networks), and such talk was positioned as important in the construction of a public sexual identity. However for others, even talking about sexuality and relationships within the interview space was difficult and upsetting; this was often because they'd never talked about such topics with another person before. For the most part, participants were mindful of the asexualised identities an ableist culture cast upon them: either they spoke of it generally (*"I'm not seen as a sexual object. I guess the perception is, disabled person, oh we're going to be on the bottom of the heap, not gonna have sexual relationships, end of story*"), or it was shown in talking about with whom they felt comfortable discussing sex. For example, many said that they would keep quiet in sex talk with non-disabled friends (though this may be for fear of voyeurism) and felt more comfortable discussing sexual matters with disabled friends where their experiences were assumed to be better understood:

> **Sally:** *"I feel really uncomfortable and unable to join in conversations about sexual partners [with non-disabled friends] because I've never had one. I don't want anyone to know that, but at the same time I don't like lying, so I try to just say nothing either way."*

Phillip: *"There's something about a disabled person who's in the same situation knowing what you've gone through, so you're more comfortable with it [talking to a disabled friend]."*

Hannah: *"I wouldn't be too honest....especially if they're non-disabled... I just think it would freak them out..."*

Pete: *"I laugh, I nod, I agree like I'm in the conversations about sex but as I said before I don't want to hear them [non-disabled friends] talking about things I can't do."*

Sally and Hannah's accounts show the skill involved in knowing what to 'reveal' to whom and when. Keeping quiet, as Sally does, is a key strategy towards managing rejection during sex talk. However, for Hannah, revealing too much (to non-disabled friends) was considered a risk to offend or "freak" people out – one which she explained required careful management amongst different groups of friends. Thus, the public management of sexual identity was that which had to be moderated, negotiated or silenced within the social context of sex talk.

Conclusions

To conclude, my analysis has shown that disabled participants lacked many of the essential ingredients of intimate citizenship. For example, many were frequently short of 'control (or not) over one's body, feelings, relationships', 'access (or not) to representations, relationships, public spaces, etc', and 'socially grounded choices (or not) about identities, gender experiences', erotic experiences' (Plummer 2003: 14). Thus, my research has shown the ways in which disabled participants were asexualised both implicitly and explicitly through a range of social processes and

spaces. For example, young disabled participants experienced significant asexualisation through adolescence, which occurred predominantly through their disabled subjectivities being rendered incompatible with normative areas of adolescent life. Disabled participants' routine experiences of lacking privacy were equally asexualising through denying opportunities for sexual expression, and exercising control, autonomy and agency within sexual life, which are central to notions of intimate citizenship (Plummer 2003). Therefore, I suggest that disabled peoples' lack of intimate citizenship and lack of a *claim for rights* to intimate citizenship is embedded in these asexualising spaces and processes. This depicts their being a sexual minority that experiences significant sexual inequality, oppression and erotophobia (Wilkerson 2002).

Moreover, participants were conscious of their ascribed public asexual identities and, in order to (re)form a sexual self, made attempts to manage their sexual identities in the public sphere in various ways. However, such management and negotiation seldom turned into sexual empowerment or emancipation from ableist discourse. For example, methods to resist exclusion and desexualisation within adolescent cultures seemed to lead to very little sexual empowerment in participants' stories, and was negotiated only through *becoming* a sexual object, either in one's own eyes or in the eyes of the (non-disabled) Other. Furthermore, much of this resistance remained within conventional notions of sexual life (e.g. having sex/being seen to be sexual), and thus served to replicate the assumptions of the very discourses that asexualise disabled people. In addition, there was little negotiation or management that could be carried out by disabled participants to obtain privacy or (re)claim a sexual self within the public spaces of 'institutional' care (e.g. boarding schools, summer camps, and respite care), particularly in a way

which does not constitute deviancy, or where any sexual pleasures which would have been obtained are shrouded in guilt. Thus, the paternalistic rules of the institution not only serve to inhibit bodily exploration complicit in satisfying sexual expression, but also reinforce disabled peoples' exclusion from intimate citizenship and their inability to claim for rights to intimate citizenship.

Furthermore, reinforcing these findings is the significant psycho-emotional impact of being desexualised and Othered, which for my participants included feelings of failure, inadequacy, and sexual shame. Heteronormative sexual education and dominant discourses of teenage sexualities served to exclude and Other disabled young people at a time where they were – as young people – trying to forge a sexual identity and develop feelings of sexual self-worth. Practical issues such as restricted spatial movement, inaccessible social spaces, peers' attitudes and the transition planning process exacerbated feelings of exclusion and inadequacy and were experienced as forms of psycho-emotional disablism (Reeve 2002). Equally, the management of the voyeuristic non-disabled gaze (required in order to (re)claim a sexual identity) involved mediating complex social interactions and thus had significant psycho-emotional consequences for disabled participants.

Chapter 5: The Intimate Relationship as a Site of Emotional Work

Introduction

This chapter explores participants' experiences of intimate relationships with both non-disabled and disabled partners. Out of 26 participants, 21 reported that they had been in an intimate relationship with a partner, with 12 of these being in a relationship with a partner at the time of taking part in my research. All except one were in heterosexual relationships; and only one disabled participant was currently in a relationship with another disabled person. The thematic analysis of what participants said about their intimate relationships suggested that their relationships were a site of considerable 'tensions'. Such 'tensions' arose in multiple sites within relationships. I contend that there is evidence of very considerable emotional work (Hochschild 1983) which participants had to carry out in order to manage tensions.

Emotional work and emotional labour are terms coined by Hochschild (1983: 7) to represent the 'labour [which] one is required to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind to others'. However, while emotional labour is the 'management of feeling to create a publicly observable facial and bodily display that is sold for a wage and therefore has an *exchange value'* (Hochschild 1983: 7, original emphasis), emotional work or management are similar forms of work that are required in private settings, such as the family or home and which have '*use value*'. In addition, some disability scholars (see Goodley 2010; Olkin 2002) argue that 'work' and 'performances' are required of disabled people in ableist cultures. This work is integral to experiencing psycho-emotional disablism, defined by Thomas (2002: 53) as 'the disablist practices that undermine psychological and emotional well-being of people with impairment'. It is

the emotional work undertaken by disabled participants that is the focus of this chapter.

In this chapter, I explore the different forms of emotional work that participants carried out within their intimate relationships. A secondary focus will be on the ways that these forms of work are gendered. The chapter begins by considering the ways in which the relationship served important functions for disabled men and women such as affirming gender identities and self-esteem, but at the same time was a space through which they could devalue themselves and be devalued by others. I then move on to look at the emotional work required to maintain relationships which participants reported as unhappy, unfulfilling and, for some, abusive. Significantly, participants said they stayed in unhappy relationships as a means to avoid further prejudice and discrimination (for example disabling attitudes) experienced outside of the relationship. Finally, I examine the tensions and emotional management required within caring relationships. I conclude by questioning the extent to which the work that disabled participants routinely undertook serves as a challenge to wider constructions which position them as inactive, passive, and unproductive (Reeve 2002) and thus resists the 'the demanding (non-disabled) public' (fitting with and being defined by non-disabled peoples' assumptions) which oppress disabled people (Goodley 2010: 92). Importantly, I also consider the *costs* of such work for disabled people.

Emotional Work

The concepts of 'emotional labour' and 'emotional management/work' (hereby emotional work) refer to the work 'people do on their own emotions in order to conform to dominant expectations in a given situation' (Exley and Letherby 2001:

115). It is more relevant to my participants' intimate relationships than 'emotional labour', which has been developed largely in relation to paid employment rather than private settings; for example, through research on occupations which require 'customer interactions' such as call centres (Korczynski 2003), flight attendants (Hochschild 1983), nursing (Henderson 2001), beauty therapy (Sharma and Black 2001) and university lecturers (Ogbonna and Harris 2004). While a focus on work in private spaces has been predominantly overlooked (Duncombe and Marsden 1998), it has been identified in some private spaces, for example, within the family (Devault 1999; Wouters 1989) and in sexual relationships (Cacchioni 2007). Identifying this work serves important functions. Devault (1999: 62) suggests that identifying the routine emotional work which takes place within family life is invaluable towards providing 'fuller, more accurate accounts of how family members work at sustaining themselves as individuals and collectivities', an understanding which, she argues, provides 'an essential foundation for equitable policy aimed at enhancing the well-being of all citizens'. Earlier works, for example Blumer (1969: 148), argue that identifying the 'invisible' work carried out as part of our daily lives can act as a 'sensitising concept' in that it can thrust previously neglected activities (e.g. childcare, caring for elderly relatives) on to the public agenda.

The term 'emotional work' is complex to describe and define (Exley and Letherby 2001). My definition of the term is borrowed from Exley and Letherby (2001: 115) and refers to the 'effort and skill required to deal with one's own feelings and those of others within the private sphere'. Conceptually, emotional work is considered to take many forms and serve a variety of functions; for example, work can be on/for the self, on/for others, be pleasurable and painful, and both collective

(see Korczynski 2003) and individual. While it is acknowledged that *all* people carry out some emotional work as part of their intimate life and through the performance of identities and the self, my analysis of participants' intimate relationships focuses on the types of work that are required of disabled people and disabled identities. The importance of labelling and examining this emotional work (and the forms it can take) is to provide fuller, more accurate and embodied descriptions of experiencing disability and impairment within intimate life.

Affirmation Vs Devaluation

In keeping with Western conceptualisations of monogamy and coupledom participants reported many benefits to being in a relationship. Conceptually, the relationship provided a 'safe space' from a range of oppressions, discrimination, and prejudices experienced in other interactions. It also served as a means to challenge ableist discourses of disabled people as sexless and as not being 'prospective' partners (Gillespie-Sells et al 1998; Shakespeare et al 1996; Siebers 2008; Finger 1992; Wendell 1996). The relationship also served particular functions which were framed by participants as *positive*. However, simultaneously the intimate relationship was a site where the disabled person could be both devalued by their (non-disabled) partner and where they devalued themselves, in a variety of ways. This section of the chapter will initially outline what participants felt intimate relationships *offered*. I then assess the ways in which disabled participants cast themselves (in their stories) as of 'lesser value' and explore how they managed the emotional work which, I propose, was an inevitable part of their intimate relationships.

Affirmation

Intimate relationships were positioned as the key that could enable participants to gain confidence, esteem, and worth. For example, following the end of her marriage to a sexually and physically violent partner, Grace used a series of short-term casual relationships to heal the (emotional) damage inflicted by her ex-husband. In particular, to get over the lack of esteem that experiencing disablist verbal abuse had caused, and to (re)gain sexual confidence:

> **Grace:** "*I started a flirtation with a colleague. It was lovely. We kissed and flirted and sometimes ended up in bed. He liked me because I was deaf, because it made me who I was. He was disabled, wore callipers. To me, his legs were sexy because they helped make him who he was. [The relationship] was totally was not threatening... I felt attractive and wanted.*"

The emphasis here for Grace is that this relationship restored and rebuilt her broken sense of self-worth, particularly in relation to her deafness and sexuality which she implied she lost during her abusive marriage. Similarly, Pete stated that his marriage was the only place in which he felt sexy, desirable and attractive: *"I don't think I ever feel attractive to myself or anyone else but my wife*". Participants also positioned the relationship as a mean through which they could 'become' gendered. For example, Tom, a 28 year old wheelchair user, said that being in a relationship increased his confidence with women generally and made him feel more desirable as a man, and Rhona, a single 31 year old university-educated woman, said that her former partner's adoration marked her validity as a woman:

> **Rhona:** "*It's nice to adore and be adored. Being in a relationship is a constant reassurance in my worth as a person and a woman."*

The relationship could, therefore, be a *gendering* space. For Rhona, it was a space in which she felt like "*a woman*". While this may also be true of intimate relationships for non-disabled people, it has a particular resonance for my participants because, at best, the relationship counteracts the degendering experienced by disabled women. Being 'adored' by a man (as that which reassures Rhona that she is a woman) fits with conventional heterosexual scripts whereby women are valued by the amount of sexual and romantic desire they elicit in a man. Therefore the intimate relationship offered a space where gender identities could be confirmed and (re)built. The relationship was also experienced as a space where participants could gain new roles and were appreciated for their abilities. Rhona spoke of how she and her non-disabled partner, who had depression, were useful to each other in the roles that they took within the relationship:

> **Rhona:** "*I could be strong for him emotionally, and he was strong for me physically*."

Rhona sets out clear roles for both herself and her partner here. In doing so she acknowledges her inability to be the physically strong partner, but casts herself in the role as the emotionally strong partner, offering a very typical gendered division of labour. This was not only limited to a non-disabled/disabled relationships. Jenny reported a similar situation with her disabled ex-husband to which she attributes to their ability travel the world, work together, and care for their son:

> **Jenny:** *"We didn't stop at anything, if we wanted to do things we would find a way. If we didn't come across a disabled toilet – although he had really bad balance he was very strong –he used to manage to lean against a wall, lift me and put me onto [non-accessible] toilets and things. He could get me up steps...I think the disabilities complemented each other, what I couldn't do... In that way we were sort of one person because what I couldn't do he'd do and what he couldn't do, I could do..."*

Jenny's experience offers a challenge to the idea that both partners having impairments is too difficult and can be unpractical, cited by many other participants as a key reason in why they wouldn't or hadn't entered into a relationship with another disabled person. However, participants who *had* been in relationships with other disabled people reported partners having impairments as a benefit. For example, Jenny also made reference to the fact that because she and her husband were both spinal cord injured, they had a better understanding of each other's bodily experiences; for instance because they both experienced incontinence embarrassment was lessened. Similarly, Grace saw her relationship with her current partner who has a disability as a more positive and trusting experience than her previous relationships with non-disabled people:

> **Grace:** *"I think there was a degree of trust that we had not yet felt previously with other, non-disabled partners".*

In addition, for people who had acquired disability in adulthood, relationships could act as a crucial comforting and supportive space which eased the transition from non-

disabled to a disabled identity. Lucille became tetraplegic during her marriage, which brought a significant change in lifestyle:

> **Lucille:** *"After I had my accident, intimacy was a problem for me. In many respects I think I was fortunate to already be in a relationship as I am not sure I would have had the confidence to engage in anything physical with someone new, even now over a decade on…. It changed everything, the enjoyment of sex, confidence, the ability to be happy. My poor partner was so bloody good about it all."*

For Phillip, who became disabled after a motorcycle accident at the age of 35, already being in a relationship at the time of the accident was useful for exploring sexual ability after injury:

> **Phillip:** *"Well, the good thing about being in a relationship [at the point of injury] is that you can experiment [sexually] early on because you've already got a sexual relationship [...] I think that was one of the biggest benefits of already being in a relationship is that... as soon as we were able to have sex for the first time it was kind of done relatively comfortably and we kind of got on [...] the emotional part of it, the psychological part of it, the kind of... the undressing for the first time part... when you're disabled."*

Thus, my participants narrated their relationship experiences in terms of what they gained; the relationship was experienced as that which could offer or affirm a sense of worth, confidence, esteem, while acting as confirmation of gender identities and roles. Significantly, it was also a place where the disabled partner could feel

(sexually) desirable, contradicting cultural representations of disabled people as the epitome of abjection, and thus offered self-affirmation and a range of benefits which defy wider discursive constructions of disabled people.

Devaluation

While the relationship could be an affirming space, most participants positioned themselves as of lesser value than their (non-disabled) partner. For example, there was a general acknowledgement by many participants that non-disabled partners were somehow 'status-raising'; but treating a non-disabled partner as a 'trophy' because they don't have a disability or impairment simultaneously reaffirms the disabled partner as abject, of lesser value, and Other:

> **Jenny:** *"...I was a bit bored of him really but it was a bit of a one-upmanship the fact that I was disabled and an able-bodied lad could be so nutty about me [...]I think it was more of an, you 'know, look at me, I can pick up an able-bodied bloke..."*

Jenny's statement that an "*able-bodied lad could be so nutty"* about her fits with discursive constructions of impaired and non-impaired bodies, where non-impaired bodies are unquestionably positioned as of higher value (Reeve 2002; Thomas 2002). However, her statement also reveals strategy and agency: that she was 'in the know' about the different values ascribed to bodies. Other people said they felt not 'good enough' to be with their (non-disabled) partner because of their disability or impairment. Terms such 'grateful' and 'undeserving' were littered throughout participants' narratives in order to express how they felt about their partner choosing to be with them:

Rhona: "*Although I knew that he adored me, I also always felt slightly as though I didn't deserve him. I am a logical person, and I know that disability puts you further down the relationship league table*."

Shaun: *"I'm very grateful to be in a relationship full stop."*

Pete: *"To be honest Kirsty, I never feel I'm good enough for my wife. I truly am a lucky bloke. I'm not just saying this for the sake of saying something kind, I REALLY mean it. I don't feel like a 'man' as I'm not very confident - I'm not very good at taking control of life situations like 'real men' do. I get tired very quickly - other 'real men' don't. I haven't got a very high opinion of myself. If something 'manly' needs doing around the house, my kids go to my wife."*

Here, Pete, a 42 year old wheelchair user who had been married to his wife for 20 years, questions his role as a man, husband, and father. Unsurprisingly he draws on dominant hegemonic constructions of these masculine roles and makes the case for why he 'doesn't fit'. This was not uncommon for many of the disabled men interviewed and is emblematic of the proposed conflict between oppressive conceptualisations of disability and Western constructions of masculinity (Murphy 1990; Connell 1995). As Shakespeare (1999: 57) suggests, 'femininity and disability reinforce each other, masculinity and disability conflict with each other'. In addition, feeling not 'good enough' was compounded by outsider perceptions of the non-disabled partner. For example, many participants made reference to the fact that outsiders considered their non-disabled partner to be 'angelic' and 'good for taking them on' (see Fine and Asch 1997).

However, also apparent in Pete's explanation of why he doesn't feel good enough for his wife is the management of emotion he undertakes. Disability scholars consider such feelings as the effect of the psycho-emotional dimension of disability (see Reeve 2002; Thomas 1999). Reeve (2002: 493) defines the psycho-emotional dimension of disability as 'a form of disablism which undermines the emotional well-being of disabled people' which, she argues, is just as powerful as structural disablism. A further part of psycho-emotional disablism, Goodley (2010: 92) suggests, is the performances disabled people are expected to *give*: 'disabled people learn to respond to the expectations of non-disabled culture – the demanding public – in ways that range from acting the passive disabled bystander, the grateful recipient of others' support, the non-problematic receiver of others' disabling attitudes'.

Another common thread running through participants' stories was that their partners 'deserved better' – the word 'better' was explained by participants to mean a partner without a disability. For example, Helen, a 20 year old student engaged to a non-disabled man, made regular references to her partner 'deserving better': "*I always think he'd be happier with somebody who could walk*", while male participants stated their partners 'deserved better' because they couldn't carry out what they defined as 'manly' duties and roles (as Pete does above). This feeling of inadequacy was also narrated when talking about sex, particularly for male participants. Heteronormative constructions of sex, which are phallocentric and penetrative, and which require the stamina, function, and performance of 'normal' and 'healthy' bodies, are argued to be particularly oppressive for disabled men (Shakespeare et al 1996; Murphy 1990). Both men and women compared themselves to what a non-disabled person 'could offer' sexually. For example, Kadeem, a single

28 year old man interviewed via instant messaging, felt 'sexually inadequate' and said that "*I wasn't gonna be enough for her coz I wasn't able to have sex properly and that she would find someone better [non-disabled] than me*". Similarly, Pete said that he regularly seeks his wife's approval following sex, showing that it is a source of considerable worry and anxiety:

> **Pete:** *"Even after 20 years of being together I still seek my wife's approval after intercourse. Even though she approves, it's not what I've already told myself... I am afraid my wife will get bored of me and wonder what it's like to have sex with an able-bodied man."*

However, while Pete and Kadeem (and other male participants) openly questioned their roles as a (male) sexual partner, some women in the sample said that they tried to 'make up for their disability' during sex with non-disabled partners. One female participant talked about how she would "*get involved in every aspect of sex you could think of, any way that was pleasurable to him"* and that *"I would put myself out to give him that pleasure even if I wasn't getting any that particular time"* so as not to be 'sexually inadequate' in comparison to her partner's non-disabled ex-wife. Another female participant told how she'd offered her non-disabled husband the chance to be unfaithful: "*I felt so bad about not wanting sex [after injury] that I kept telling him to have an affair*". The strategies employed by these women (both of whom are wheelchair users) are, I propose, indicative of low sexual self-esteem which is widespread among disabled women generally (Mona et al 1994; Gillespie-Sells et al 1998), and more likely to occur in women with severe disability 'because they tend to be furthest away from cultural constructions of ideal feminine beauty' (Hassouneh-Phillips and McNeff 2005: 228; see also McCabe et al 2003). Such

attitudes are inherently normatively gendered, being underwritten by dominant heteronormative constructions of sex which privilege male sexual pleasure and desire, and which contribute to the 'male sex right' (Jeffreys 2008). These women's actions were accomplished through means which positioned their own needs and wants as secondary to that of their non-disabled partner – thus devaluing themselves in the process.

The Relationship as a Problematic Space

For many, another source of 'tension' centred on a strong desire to be partnered (or be seen by others to be partnered), even if the relationship was unhappy, abusive, or unfulfilling. Participants voiced a variety of reasons as to why they stayed in relationships, which often went beyond (romantic) feelings for their partner. Significantly, an unsettling finding is that while some participants stayed in situations where they were unhappy, others stayed in relationships where they experienced abuse and exploitation. This finding echoes existing research which suggests that disabled women put up with abuse within relationships as a consequence of their internalised oppression (see Gillespie-Sells et al 1998). Reeve (2004: 92) states that internalised oppression 'is one of the most important manifestations of psycho-emotional disablism because of its insidious effects on the psycho-emotional well-being of disabled people'. I will detail these findings, beginning with disabled peoples' fears of 'starting again' and 'being accepted' by new partners, before looking at the forms of abuse that some participants experienced.

Participants reported staying in unhappy and unfulfilling relationships for variety of reasons: because of the fear of rejection in finding a new partner; worries about 'starting all over again' in terms of disclosure and acceptance with new partners; fearing that 'nobody else will want them' and a fear of or not wanting to be single again. Thus a relationship, regardless of its quality, was often considered to be a better option than being without a partner at all. Frequently, this meant that some participants stayed in relationships just for the sake of it, or put up with situations where they were unhappy, or in one case, had relationships with partners they neither cared for nor found attractive. These findings correspond with a recent report by Leonard Cheshire Disability (2008: 5) which suggests that 'disabled respondents had lower expectations than non-disabled people for their relationships'. The prospect of being single, and thus no longer with a partner, brought with it a range of fears. Such fears often originated out of the amount of time it initially took to find a partner:

> **Jane:** "*I am unhappy [in the relationship] a lot. But I'm scared no one else would accept me. I just think people don't accept people who are different"*
>
> **Robert:** *"I wasn't in love for the last 3 months but was scared of being single, especially out of uni and knowing how hard it is to really get someone to see thru everything [his disability]"*
>
> **Shaun:** *"Because of my disability I thought 'oh well, I need to stick with this because I might not find anybody else'..."*
>
> **Tom:** *"I suppose because I am disabled it gives you the worry about getting a girlfriend, you kind of hold onto it [the relationship] for dear life, until it's like flogging a dead horse and that's no good for anybody."*

Many of these statements are not surprising when considering the significant difficulties many disabled people may face when finding a partner or relationship, as has been outlined extensively elsewhere in the literature (Shakespeare et al 1996; Howard and Rintala 2001). Phrases like 'sticking with it', and 'flogging a dead horse' emphasise the *effort* required of staying in relationships which aren't fulfilling. However it was clear that participants found this *less* effortful than carrying out the work involved in finding and settling with a new partner, which was explained to be extensive. Having to disclose impairment and disability to a new partner was cited by many participants as a reason why they stayed in their current relationships. Goffman (1963: 14) argues that an 'abomination of the body' (e.g. non-normative embodiment, impairment, or 'visible' illness) inevitably affects selfhood because such 'abominations' cause a failure to meet the virtual identity expected by 'normals'. When the impaired person fails to meet this expectation, the gap between this failure and their actual identity creates stigma and they are discredited. Thus, the 'risk' of discreditation (and thus management of stigma) was visible through many participants' stories. For example, Jane, a 21 year old female who was in a long-term relationship with a non-disabled man said, of finding a new partner: *"I would have to go thru that whole thing about opening up to them and telling them about my feet. To be honest I would like to never have to do that again".* Other participants said that the point of disclosure could be a time of rejection and that they had experienced discreditation (Goffman 1963):

> **Helen:** *"Like, I have spoke to people before [disclosed] and they have dropped [you] afterwards, after you've told them... but then, you know,*

there's a point where if you tell them first you don't have to go through that I suppose."

Helen was talking about her experiences of meeting partners online, which due to access and confidence reasons, was a preferable way for her to meet partners at that point in her life. When she first started meeting people online she would 'edit' her pictures to hide her wheelchair so that she could get to know a prospective partner (this was a common strategy for participants who had used online dating sites) (see Blyth 2010). These actions are exacerbated by a profoundly visual culture and practice inherent to online dating. Reeve (2002: 499) suggests that the 'non-disabled gaze' (on the impaired body) is 'influenced by stereotypes and prejudices about disabled people' and that the 'disciplining power of the gaze can leave disabled people feeling ashamed, vulnerable, and invalidated' (see also Keith 1996). Through 'hiding' impairment in this way, participants were actively managing the 'non-disabled gaze' (Reeve 2002) and the risk of discreditation (Goffman 1963). Helen talked of becoming invested with people to a certain stage and then experiencing a very negative reaction (at best, not hearing from the person again) after swapping photos which revealed she was a wheelchair user. Thus, despite her work she was rejected, which she says felt "*horrible*". Therefore, the 'new' visibility of her impairment was central in taking her from discreditable to discredited (Goffman 1963).

Other participants made reference to the considerable time it could take for a (non-disabled) partner to learn how to do certain tasks that may need to be carried out, for example basic caring duties. Introducing partners to this knowledge and teaching them specialist knowledges about living with impairment (and what it may

involve) took considerable work on the part of the disabled person. Moreover, this work involved putting up with 'bad' care whilst non-disabled partners went through the learning process (discussed later). This 'investment of knowledge' made some participants hesitant to leave relationships. As Robert, a 28 year old wheelchair user, expressed: *"it [care] progressed with each partner over time. So when that's overcome you feel inclined to stick there, even if it ends up not being right."*

However, other participants said that they stayed in relationships literally for the sake of having a partner. This was for a variety of reasons, from not being lonely to having a partner being a public sign of worth, to both themselves and other people:

> **Robert:** *"I've always felt and discussed with my best friend in a chair, how we need a girlfriend as we are sexual beings but also to kind of show we are ok... "Look a real girl likes me, I have sex with her and we are in intimate - I must be ok, world""*.

Using a partner or relationship as a symbol of being "*sexual*" and therefore "*ok*", as Robert puts it, is a strategy which publicly acclaims the disabled person as a sexual person and challenges notions of asexuality and sexual inadequacy. This is evidence that, as De Vault (1999) suggests, merely *surviving* oppression is work in itself. Thus 'putting right' the ableist assumptions which Robert feels are cast upon disabled male bodies was conducted through relationships with non-disabled ("*real*") women. However, this work, which takes place both for the public and the self, can also be argued to be exploitative and objectifying for the non-disabled women who are utilised for such public displays.

In addition, feeling that the current partner offered the 'only opportunity' to

have a relationship was also cited as a reason to stay in an unhappy relationship. Often these feelings were grounded in the participant's previous belief that, as a disabled person, they would never enter a relationship. For example, speaking of a previous relationship, Kadeem, a single 28 year old male with a progressive impairment, said that it was "*a dream come true*" to find a partner who accepted him. Notably, many participants talked about how they had felt that a relationship, love, and sex was 'out of reach' as a disabled person, and often, that such thoughts began at a young age and had been confirmed by family members or friends (see chapter four). This finding supports Shakespeare et al's (1996) suggestion that the institution of the family can be an oppressive space through which disabled people are socialised. They propose that, for disabled people, this is different from other minority identities (such as ethnicity) whereby oppression is experienced by the collective group and thus is shared between family members. However, for Graham, a 52 year old single male, being in a relationship 'for the sake of it' meant being in relationships with women to whom he was not attracted and did not like:

> ***Graham:*** *"I didn't like her, she was very fat... my attitude was entirely 'I've got no choice... she likes me for some reason and it's her or nothing'... I never liked her, never fancied her; I didn't like her touching me."*
>
> ***Kirsty:*** *"How does it feel to be with people you don't feel... you don't actually like?"*
>
> ***Graham:*** *"It's horrible. Well it's horrible but that's it, there's no other option. You either just spend your life entirely alone or try and be with*

someone who's willing to be with you for whatever reason. Erm, it's horrible."

Significantly, Graham was one of the most isolated people interviewed. He lived alone, said he had no real friends or family, rarely went out, and spent much of his time alone which contributed to his isolation:

> **Graham:** *"I can go into a shop and say "Can I have one of those please?" and I literally have not spoken [to another person] for 2 weeks, so it comes out all [whispers with breath and clears throat] as I just can't speak 'cos I've no-one to talk to."*

Graham's words above are indicative of the extreme marginalisation and isolation many disabled people experience. Few other participants experienced such extreme isolation. Such words add context to his reasoning to attempt relationships with people he doesn't like as he feels "*there is no other option*…" In short, anyone is better than no-one. The fact that Graham experiences feigning his feelings and having sexual relations with people he isn't attracted to can be seen as forms of emotional work. Undertaking such work takes great effort and time and Graham talked at length about 'forcing' his feelings within his relationships. In addition, because of the relationship context, Graham's performances were required to appear *genuine*. Hochschild (1983) calls this 'the search for authenticity' – the requirement for an emotional display to not just be presented and performed, but appear sincere and authentic; thus the requirement is to do 'deep acting' (Hochschild 1979). This, she argues, comes at a higher cost to the person as they can 'suffer stress and be susceptible to burnout' (Hochschild 1983: 187). The end result, states Hochschild (1983), is that the person ceases caring altogether and becomes detached from others.

Thus, the *costs* of this work for Graham, which he undertakes rather than be alone (as a strategy to resist his isolation and marginalization), may result in him being more detached which may serve as counter-productive to future relationships.

Abuse

Some participants had such a strong desire to be partnered that they put up with a range of what I identify as harmful situations. These included, for example, experiencing a range of abuses from a partner (sexual, physical and emotional), experiencing discrimination and prejudice from a partner's family, and accepting a partner's infidelity. Notably, I do not refer to the disabled participants' in such situations as victims or exploited. This firstly is because this is seldom how they labeled themselves and narrated their experiences; and secondly, because constructions of vulnerability and victimhood do little to protect or empower disabled people. Rather, disabled scholars suggest framing disabled people as 'vulnerable' actually reinforces abusive and violent behavior towards them (Waxman-Fiducca 1991; Hollomotz 2010). Thirdly, this is because the label of 'victim', I propose, is not representative of the considerable (emotional) work involved in living with or enduring abuse. Being routinely humiliated, frightened, hurt, intimidated, scared, and abused as part of one's daily life, as well as the labour involved in hiding it from the outside world, takes serious *work*. Thus, for the purposes of this analysis, managing abuse, discrimination, and exploitation are considered as forms of emotional work.

Many participants revealed that they had experienced a form of abuse, either sexual violence, physical violence, and emotional abuse, throughout either their current or past relationships. According to Women's Aid (2011), sexual violence

includes situations whereby 'partners and former partners may use force, threats or intimidation to engage in sexual activity; taunt or use degrading treatment related to sexuality; force the use of pornography, or force their partners to have sex with other people'. Physical abuse relates to any harm of the physical body (Women's Aid 2011). Notably, both men and women had experienced abuse, though it was only female participants who had experienced sexual or physical violence alongside other abuses. Grace, a 58 year old Deaf woman, had suffered extreme abuse at the hands of her husband:

> **Grace:** *"He wanted (and got) sex at least twice a day every day. Sometimes we had sex more than twice a day – even up to five times a day. It didn't matter if I had my period or if I felt unwell or was pregnant. He wanted sex. If I was physically unable to bear penetration, I had to give him a hand job or a blow job. If I refused, he made my life a misery, sulking and getting angry and taunting me. It was easier to do as he wanted. I seldom ever enjoyed it. Over the years he became very abusive. I was treated like meat, raped, sodomised. He told me I was boring and useless, only good for a fuck. I started to almost believe it. My confidence was at rock bottom. In my heart I knew that what he was saying was wrong but I felt helpless. And there was my deafness. I had left school with no qualifications, no career. A dead end job and an early marriage and children meant I had hardly any skills outside the home. He isolated me from my friends. Having said all this, he was not a monster and there were good times. But the abuse was always there. He could not cope with*

me being deaf; as my deafness increased, he found it harder. He did not want a deaf wife. He hit me a few times."

Grace's account shows the extensive violence some disabled women (and women in general) experience. It also shows the way in which disability (and disability hatred) can be imbricated within disabled women's experiences of abuse. Importantly, Zavirsek (2002: 270) calls for the de-individualisation of sexual violence experienced by disabled women in order to look at what he calls 'the institutional arrangement of domination and subjugation' which determine disabled peoples' bodies as sites of violence. In this case, rather than her impairment as making her more vulnerable, Grace cites an inaccessible education system (that left her with no qualifications) as her reason for marrying early, which in turn meant she had few skills outside of the home and thus was more isolated and 'vulnerable' to abuse. Grace's account, I suggest, reveals the '*survival* work' she had to carry out in order to maintain a 'relationship' with her husband. Similarly, Jenny, a college-educated spinal cord injured woman, experienced a physically violent episode at the hands of her disabled husband, to which she attributed the end of her marriage. Jenny left the marriage directly after this incident despite being told by police, whom she called for help, to go back home because it was 'just an argument'. Upon leaving, Jenny had to organise a room at her mother's sheltered accommodation because it was the only accessible venue she could find.

These women's experiences support calls for better accessibility of women's domestic violence services (Thiara et al 2010; Chang et al 2003). For example, mainstream (domestic) abuse organisations do not consider disabled women within their remit, often, because of their asexualisation and the assumption that they do not

form intimate partnerships (Zavirsek 2002). Thus, domestic abuse organisations rarely cater to the needs of disabled women (Thiara et al 2011). This is despite the fact that disabled women, in comparison to non-disabled women, are more likely to experience sexual and physical violence in their lifetime (Sobsey and Varnhagen 1989; Hassouneh-Phillips and McNeff 2005; Shakespeare 1999). Although, such statistics have been deemed as unhelpful by disabled feminists because they reinfirce discourses of vulnerability and victimhood (see Morris 1991; Waxman, 1991), it is the case that disabled people experience less privacy in their lives, have increased reliance on others and institutions for care, and experience increased access to their bodies by non-disabled people – all of which may increase their chances of experiencing abuse.

Both male and female participants stated that they had been belittled, called names, lied to, treated badly and humiliated. According to Women's Aid (2011), emotional abuse includes

> 'destructive criticism, name calling, sulking, pressure tactics, lying to you, or to your friends and family about you, persistently putting you down in front of other people, never listening or responding when you talk, isolating you from friends and family, monitoring your phone calls, emails, texts and letters, checking up on you, following you, and/or not letting you go out alone'.

Participants spoke about such abuse in a variety of ways and did not refer to their experiences using such terminology. None of my participants identified their experiences explicitly as 'abusive' but most were aware that such situations were both 'not right' and 'harmful'. I suggest that this is because emotional abuse is more

‘covert’ in nature and thus more complex to identify, define and describe. In addition, it may be because, as Goodley (2010) suggests, disabled people experience discrimination and prejudice as part of their daily lives and so such experiences are normalised in the context of the disability experience.

Much of the verbal abuse participants reported centred on disability, the (impaired) body, and/or sex. This is a typical behaviour within abuse and bullying in that abusers and bullies often identify sources of pain and hurt in order for abuse to be more effective. For example, Graham, a physically disabled man who was very insecure about being what he defined as ‘sexually inexperienced’, said that one partner would comment on his “*ugly*” legs and another partner would call him “*lousy*” and an “*idiot*” during sexual relations in response to him asking her what to do sexually. Similarly, Bob, a man with physical and sensory impairment, spoke of the way in which two female partners had “*wasted very little time circulating the news of my [sexual] non-performance”* after breaking up, and said that his former partner had regularly made reference to his inability to ‘sexually fulfil’ her. Helen, aged 20, told how one boyfriend used to call her “*square*” in relation to the “*wideness*” of her body shape, which she says is caused by using a wheelchair: *“obviously I’m sitting down so I’m fatter”*. Another boyfriend, the father of her baby, would taunt her about the “*boring sex*” she ‘gave’ and, she admitted, “*he goaded me and called me names*” about the shape of her arms which are thin because of muscle degeneration. Helen said that these incidents “*will always stay with her*” and cites her disability as the reason for taking “*a lot of crap from people*”. Tellingly, she said that if she were non-disabled, she would not have put up with it; and yet, a lot of non-disabled women do.

Some participants said that they had been emotionally abused by their non-disabled partner's family and described the forms it took; for example, being excluded from family events, subject to prejudice, publicly humiliated, experiencing non-disabled partners being cut out of the family, and verbal abuse:

> **Jenny:** *"His father, he told me to f-off; he came out to my car and told me to fuck off. He [partner] didn't have any disability... Yeah... "fuck off you cripple and leave my son alone"".*

Jenny said she experienced this kind of reaction more than once with different partners. However, at the same time, other participants said that they were 'hidden' from, or kept from meeting their partner's family and friends, for fear they may cause embarrassment:

> **Tom:** *"I think maybe she was ashamed of me being disabled. Looking back on it now, it's a pretty kind of – like it wasn't a very healthy relationship to be in, erm... It really, really, really, really had a big impact, it was horrible."*

While this could have been non-disabled partners' attempts to save a disabled partner from much of the above, this was not how it was experienced or narrated by participants who had experienced 'being hidden'.

Abuse by partners went beyond verbal forms to more severe forms of emotional abuse, such as exploitation, manipulation and humiliation. For example, some participants talked about the ways their self-esteem was (deliberately) lessened by partners reflecting and focusing on the things they couldn't do and making a point of it to humiliate them. Others said that ex-partners had been unfaithful and that they

had been cheated on multiple times; while some said that ex-partners had controlled and exploited them. Jane, a 21 year old student, talked about the difficulties with her current (non-disabled) partner. She implied that she relies on him a lot for help:

> **Kirsty:** "*In what ways does he help you?"*
>
> **Jane:** *"... Makes me wear my splints, walks in front of me on the stairs so I don't fall, checks my feet for cuts as I can't feel them, comes to appointments with me..."*
>
> **Kirsty:** *"How does it feel that he does those things for you?"*
>
> **Jane:** *"Loved. That most of the time he understands. It's just the odd times that he doesn't and he gets angry. Like, I'm not doing something right. I always blame myself even though I'm not wrong. And I generally just cry. I don't know any other way to react."*

Jane said that these situations make her feel like "*the weaker one in the relationship*". She also talked about how her boyfriend can be 'insensitive'; for instance, he bought her a pair of high heels which she can't walk in because of her impairment, for Christmas. Not being able to wear heels (and thus wear feminine dress in the way she perceived it) was something Jane raised many times throughout the telling of her story. She talked about wanting to be able to walk in high heels "*more than anything"* and her boyfriend buying her some as a gift in full knowledge of this*, "felt like an insult"*. She said*, "I had to put on a front when I opened my Christmas present because he just hadn't thought about how much it would actually hurt me."* Jane went on to describe how she kept this sadness quiet for three months at which point it broke out into an argument whereby her boyfriend called her ungrateful. Later, when talking about the aspects of sex she doesn't enjoy, Jane reported that her

boyfriend requests she wear these very same high heels during sex for his sexual pleasure. This, she says, makes her feel frustrated: *"because I don't want to just wear them during sex. I want to wear them out."* Putting on a front, feeling sad, keeping quiet, and being frustrated are forms of emotional work that Jane had to carry out in order to manage this situation. At the same time, being reminded of this emotional pain (and feeling of inadequacy around not being able to walk in heels) was something she had to endure during sex, for the sake of her partner's pleasure.

Care

The carrying out of caring tasks, whether carried out by a partner or contracted through the services of a personal assistant (PA), was evident in most relationships where there was both a non-disabled and disabled partner. Thus care was a significant factor within participants' stories. The literature on caring is extensive; from both non-disabled feminists who focus upon the (female) carer (e.g. Arber and Ginn 1992; Stacey 2005; Twigg 2000; Marks 1997; Waerness 1984; Graham 1983) to the theorising of care from a disability perspective where the focus is upon the cared-for (e.g. Keith and Morris 1995; Morris 1997, 2001; Keith and Morris 1996; Smith-Rainey 2010), highlighting the contested nature of care and caring (see Hughes et al 2005). This analysis contributes to this body of literature through exploring the types of *work* required of the cared-for, which were found to be integral to maintaining functioning care relationships.

Significant tensions were experienced in the caring relationship. An initial tension was the rigid separation between the roles of 'carer' and 'partner', for which many participants strived. Separating these roles was seen to 'protect' intimate life and limit dependence for the disabled partner, but this could be an unrealistic goal

that was rarely problematised by disabled participants. When care was carried out by a partner it could involve constant power negotiations and management by the disabled person in order to maintain autonomy, control, and independence. Significantly, such negotiations were not always successful and often resulted in the disabled person needing to carry out extensive emotional work. In addition, when professional care was contracted via PAs it equally required skilful management (and work) by the disabled person, particularly in terms of a partner's jealousy, confusion over roles, intrusion, and privacy.

A strict separation of the role partner and carer featured in many stories. For many, conflating these roles was a source of real discomfort. While this rigid distinction was strongly asserted, often it was not the case in reality. For example, sometimes disabled partners would need assistance because (professional) care was not available, or it was (at a particular moment) more practical for a task to be carried out by a partner. However, many participants were vehement when talking about the divided roles of 'partner' and 'carer'. The following quote is taken from Lucille's journal. Lucille is a 36 year old woman who became a tetraplegic at the age of 23. She had watched a television programme about partners and care the night before and had reflected on it in her journal:

> **Lucille:** *"...The wife [on the programme] referred to herself as her husband's carer/partner. This really angered me. I understand that relationships are different, largely through necessity when someone has a disability or illness. However, as soon as you start to refer to your partner as your carer I think you're descending down a slippery slope. I'm not deluding myself. My husband does a hell of a lot for me and does*

'care' for me. However, he is my husband first and foremost – my friend, my lover, but not my carer! I would never refer to him as my carer... I hate that aspect of my disability – the fine line between carer and partner. I don't want [partner] to be my carer but he is some of the time. I hate the word "carer", it's so old fashioned, like "handicapped"."

For other participants the blurring of the two roles was seldom acknowledged or problematised, for example, they would make a rigid distinction between these roles and then proceed to talk about the caring tasks their partner would carry out. Partners were very rarely referred to as carers despite the fact that most people said that their partners carried out care for them – which was more often referred to as 'help' as opposed to 'care'. Notably, protecting intimate life was voiced as a central reason in keeping these roles distinct. In order to retain and 'protect' their sexual autonomy and agency, some participants did not want their partner to see them as 'dependent' and therefore sexless. For example, Helen said it would be much easier for her partner to help with some tasks, but that she chose her mother to do it for fear it would "*get rid of any sort of sexual life thing".* Similarly, Rhona told how her ex-partner wanted to care for her but that she firmly rejected this offer on the grounds that it "*would have taken some of the mystique out of our physical relationship*". Shaun, 33, who had become a wheelchair user as the result of an accident at the age of 10, and his non-disabled partner Hannah (who were interviewed together), said the dynamic of their relationship changed considerably and that any sexual life stopped completely when Hannah had to step in and take over the role of carer when Shaun's PAs was unavailable. Shaun went on to explain that he would never want Hannah as a full time carer:

> **Shaun:** *"I used to work for an independent living advice place and through meetings and groups that we had there are people who say that it takes away from the relationship, you 'know, that person... you might think it's alright to begin with but you kind of slip into it subconsciously and then over time that person just becomes the carer and you lose all other aspects of your relationship..."*

Like Lucille, Shaun describes a partner 'slipping into' a carer role, as if such a role begins tentatively to then become all-consuming where the partner-identity becomes unrecognisable. However, for some participants the presence of caring tasks was not in conflict to sex or intimacy and could reinforce sensuality and intimacy. For example, Robert said partner-caring could add "*closeness*"; Jane said it increased her "*emotional connection*" to her partner, and Tom said that partners caring for him could be *"quite beautiful – if you can believe it... quite tender and loving"* (see Smith-Rainey 2010). However, such views were in the minority in comparison with the majority who experienced the roles as conflicting.

At other points, it was clear that the disabled participant carried out significant (emotional) work in their role as a *receiver* of care. For example, many participants narrated care from partners as something they had to 'put up with', in that partners did not carry out tasks correctly or in preferred ways. Even though this was a central source of frustration and often anger, it was a situation where the disabled partner had to show incredible tolerance, grace, and be grateful – often when they fervently felt the opposite. Thus, in order to manage the 'feeling rules' present within the caring relationship (Hochschild 1979: 552), rules which 'govern how people try or try not to feel in ways appropriate to the situation', disabled participants had to show

emotions which were 'appropriate' for those receiving care (see Morris 1989). Disabled men and women carrying out this extensive emotional work (as a care receiver) was crucial towards maintaining functioning care relationships and intimate partnerships. At its most extreme, this involved avoiding, or being submissive in, arguments with partners (for fear of withdrawal of care); being passive and keeping opinions/points of view to themselves; and taking on a role which, if paid-for care in the form of PAs was in place, they wouldn't adopt.

Many people talked about the 'bad' care their partner offered. Helen, 21, talked lengthily about her fiancé and care. Having been cared for by her mother all her life, she revealed she was reluctant to change this arrangement until she eventually moved out of the family home. However, her fiancé, who she saw at weekends (because he was a university student), had shown great willingness to take over this role from her mother. This was not a change that Helen welcomed for many reasons (such as her sex life) but one which she felt she had to accommodate because of his willingness to care. She talked extensively about having to 'teach' him, and allow him the time to learn her preferred way particular tasks are carried out. She was clear that in the meantime this meant her putting up with care that is "*a damn site worse*" than from her mother and for which she had to be "*tolerant*" and "*grateful*" because "*he could just tell me to get stuffed!"* She said that it often dictated what she could wear, as she would pick garments that she knew her partner could cope with, regardless of whether she wanted to wear it or not. To add emphasis, she offered a story of a situation where this was not possible, and the impact it had:

> **Helen:** *"We went to London for this thing... [I had to wear] like an evening dress...Oh. My. God. [Laughs] I was gonna travel down in the*

dress and thought 'don't be silly, he can put a dress on' but oh my god we had an absolute fight over this dress, we couldn't get it on. It wasn't that difficult but it had a lace overlay thing and he couldn't figure out how to put my arm in it, so I was absolutely balling my eyes out, stressed, because we were late as well and you just think [sighs] 'how much easier would it be?' you know, you just get depressed, you just get upset... But you blame yourself because you think 'if I'd have just got mum to put it on me before I'd left or'... but then obviously he gets stressed as well and I'm balling and shouting and you reach a point where... you can't, you lose the tolerance in a way because you think 'for god's sake, how thick are you being? Just put my arm through the hole!' And it just leads into a major heated argument..."

In this account, Helen talks a lot about being upset, depressed, and blaming herself. The interview often became a space for people to vent such feelings regarding the standard and quality of care from their partner – presumably because such feelings would make them appear ungrateful or unappreciative if voiced in other spaces. Shaun's non-disabled partner Hannah offered a chance to see the perspective of the non-disabled partner. Hannah talked about times when Shaun's personal assistant was unavailable:

Hannah: *"I may be less respectful of Shaun's body as a carer because... and Shaun is less likely to say something to me than he is to the carer [PA]. Like if I'm in a mood or I'm in a rush, like this week, I know that I've probably not done things exactly how Shaun would like it but I know he won't say anything because he doesn't wanna piss me off and I won't*

necessarily offer because I'm in a rush. I do see it as a job, in that sense and... That's something that I struggle most with is the kind of resentment because I've often said to Shaun, "I wonder if you're with the right person? You 'know, someone who's more caring than me!" Because if I do a lot of stuff for Shaun I get backache and then feel resentment towards Shaun, and that's something we've talked about haven't we? [To Shaun] About those feelings... and Shaun feels a lot of guilt generally to me and towards anybody erm... so that's something that we really had to look at, and most of the times when I have to help Shaun out, like a holiday, or like this week, I can mentally prepare myself and I am ok with it. The things I find difficult is the middle of the night or, you 'know, then I might not be so nice... [Laughs] And, you know, spur of the moment things or if [PA] is late or... it's the things that I haven't expected, that's when I find it quite difficult and I really feel like Shaun owes me a favour even though in my mind I can say 'he doesn't owe me a favour, he needs this' but somehow I am keeping score when things like that happen."

Hannah is incredibly honest about how she feels when having to take on a caring role for Shaun. Her account shows an awareness of the emotional work Shaun carries out: his keeping quiet; having tasks carried out in ways that aren't preferable; feeling guilty; and being resented. It also shows the considerable emotional work that many carers undertake. Importantly, though, the (emotional) work of those in caring professions (and unpaid carers) is well documented, for example, nurses (Henderson 2001; Millward 1995; Smith 1992; Frogatt 1998) and personal assistants and care workers (Earle 1999; Treweek et al 1996), while the emotional work of the cared-for

is much less so (James 1992; Morris 1997; Hughes et al 2005). Moreover, Hannah's account shows the problematic changes that caring can bring to a relationship which they both recognise as loving, intimate and valued. Often these problematic dynamics increased when the disabled partner had an increasingly level of need, for example, on becoming ill or through impairment progression. Pete told a story of when he was admitted to hospital and then discharged with a catheter inserted which caused him intense pain and anxiety about cleanliness. He explained this as a point of conflict in his relationship with his wife:

> **Pete:** *"I developed an obsession with cleanliness with myself. I used to seek assurance from my wife. I got obsessed which caused a few problems around caring... I never thought the catheter site was clean enough – I was scared of infection. So I'd ask my wife to clean it over & over. We'd sometimes argue, which I hate - my wife is so good to me. I'd nearly always have infections and I didn't how or why, I was clean. When the catheter needed changing I'd drink lots of alcohol, beer, or whisky to help with the pain & spasms. This resulted in vomiting. My wife would get annoyed."*

Likewise, Gemma, a 42 year old lesbian who has an immunity impairment which causes her to get ill sometimes, had an agreement with partners that she only receive care from them when recovering from periods of illness. She told how a cancer diagnosis meant she had to be cared for full-time by her then-partner which she said was very difficult to cope with. Gemma said that the diagnosis "*affected the whole dynamic of our relationship"* particularly because her partner began to control basic things like the types of food she ate, for example, introducing an anti-cancer diet.

Gemma said "*I felt like crap and I just wanted food I wanted to eat, you know. I do not want a cabbage smoothie, and I would quite like to throw it out of the window!"* Gemma said that the relationship ended when her partner got "*too into the role*". Prior to that, she had to manage her partner's anxiety around her cancer (when she was the one who had it); Gemma said that this anxiety affected the type of care her partner offered. Gemma stressed that she felt she had lost power, and therefore control, autonomy, and agency. Significantly, this emotional management had to be carried out at a time of great emotional anxiety that a cancer diagnosis can bring. This finding shows that emotional work often also involved work on or for others (Hochschild 1979; Exley and Letherby 2001).

Furthermore, the majority of participants who had received care from a non-disabled partner said that this affected the way they dealt with conflict within the relationship. Caring tasks were conceptualised as something the non-disabled partner could offer, rather than a requirement. Thus, it was also something that could be taken away. Participants mentioned that as a result they avoided conflict or arguments with a partner, took on a submissive role generally and, especially in arguments, as a strategy to ensure continued care. For example, Helen chooses to take on a 'passive' role generally in her relationships (with her fiancé and mother as carers), to ensure her care needs are met:

> **Helen:** *"The trying-to-be-nice if you're having an argument, that definitely...because you've kind of lower your boundaries... Like, just go along with things that you really don't want to do..."*
>
> **Kirsty:** *"Do you do that constantly?"*

> **Helen:** *"Yeah... Consciously, a lot. I know I do things just 'cos it's easier, definitely. Just to not cause trouble, really..."*

Helen's work to be passive is *functional* and her performance of gratitude must appear genuine in order to not disturb her care arrangement. The fact she does this work consciously, I suggest, shows that she experiences this power imbalance in a very real way. Specifically, some participants said that their need to receive care from partners affected their power in the relationship, with arguments being positioned by many to increase this imbalance of power:

> **Robert:** *"If an argument arose could I really defend my point even if I'm right, but then ask for help knowing they're annoyed with me?*"

> **Terry:** *"I feel that I can't – if I'm with a girlfriend – I know that I can't be easily irritated by things they do, because I've got to rely on them to help. So, erm, in the past I haven't really had an argument with a girlfriend unless – unless it's been at a time where I don't need them for any help."*

Terry, a 20 year old university-educated male, says he deliberately avoids arguments with partners except at times where he doesn't need help. This is evidence that disabled people who receive care from partners have to consciously mediate and manage these complex relationships and do so through careful strategies. Secondly, Terry's account (and the accounts of others) shows the active role undertaken as a care *receiver*. Disabled participants, here, certainly are not dormant receivers of care, but narrate their stories showing the (active) role they play. Thus, I argue that being cared for by a partner can mean undertaking a variety of forms of emotional work –

tolerance; ‘submission’; graciousness; the assessment of when and when not to assert oneself; and managing a complex set of power relations – in order to continue to receive the care that they require.

Tensions around caring tasks were often not alleviated through ‘purchasing care’ in the form of personal assistants (PA) (see Vasey 1995). For some, this also involved an equally skilful management of power (and people); in particular, balancing the needs and wants of a partner with the needs and wants of a PA. To add context, the relationship between a PA and a disabled person can be both intense and intimate. PAs can be seen by disabled people in a variety of ways: as crucial providers of care; as enablers; as friends; as access to independence; and/or an extension of the disabled person’s body (Shakespeare et al 1996; Morris 1989). Thus, they can be critically important in a disabled person’s life. In addition to this, spending considerable amounts of time with one another, for both the disabled person and the PA, can build strong emotional relationships and friendships (see Woodin 2006). For the disabled participants who used PAs and were in relationships, this could be a real source of friction and a situation where they were required to carry out considerable management:

> **Rhona:** *“I see my carers as facilitators, whereas my ex saw them as an infringement of our privacy. I could see his point, and obviously wanted to spend more time just as a couple, but I was not prepared to compromise my independence. I would rather be independent as an individual than independent as a couple.”*

The last sentence of Rhona’s quote reveals the disparity of how PAs can be conceptualised by both the disabled and non-disabled partner. Many participants

talked about how purchasing care compromised their independence as a couple; particularly when going on holiday or doing something outside of their usual routine. In order to have privacy as a couple, on these occasions the non-disabled partner had to take over caring responsibilities which, as has already been established, can be problematic. Other participants said that their non-disabled partner could be jealous, and that managing this took skilful work:

> **Rhona:** *"The intensity of the relationship between myself and my carers was problematic for my ex-partner. He was very jealous of the time I spent with them, and was especially unhappy if I employed a male carer. It was difficult and confusing for my carers when he visited, as their role changed, and my relationship with them was temporarily compromised. It is difficult for me to negotiate everyone's feelings, and I often prioritised my carers' feelings over my partner's needs, which I believe also led to the break-up. It is a very delicate balancing act, and I often think that I do not have space in my life for both carers and a partner."*

For Rhona, carrying out the "*delicate balancing act*" involved negotiating feelings and prioritising different people at different times. Her admission that she feels that there may not be space for both a partner and a PA in her life shows the sizeable extent of this work. Moreover, it explicitly reveals how problematic maintaining independence and autonomy can become when a disabled person who utilises personal assistance enters a relationship. This challenging dynamic, of a close relationship (both logistically and emotionally) between three people (disabled person, partner, and PA), was described as very difficult by other interviewees.

Mark, who had been in one relationship with a partner who did not live with him, reflected on living with a partner and a PA:

> **Mark:** *"Living with me involves living with PAs as well, how does that work? If people are not tolerant of PAs then that makes things difficult, then I'm sometimes in a situation, 'cause my ex-girlfriend, it's quite tricky, 'cause there was PAs and the ex girlfriend and sometimes trying to get... you can't make everyone happy at the same time. [Pause] But, I was trying to make her [girlfriend] happy first, like a nice happy family. But, different PAs bring different situations I guess."*

Mark, a 35 year old single male with a progressive physical impairment, later elaborated on the upset his then-girlfriend experienced when he had talked to his PAs about their sex life. Mark considered his PAs to be friends and thus, to him, discussing his sex life was appropriate. To his girlfriend who saw PAs as workers it was not. This, again, shows the different meanings that disabled and non-disabled partners can attach to PAs and the strain this disparity can produce. There could also be conflict in the way that caring responsibilities were 'shared out' between a partner and PA. Terry talked about a strategy where he offers partners the choice of caring tasks in comparison to a PA. He says this can be very difficult, but wants partners to have "*choice and control*". Employing a PA was also positioned to impact upon intimacy with a partner, "*a Catch 22*", in which the presence of a PA was important for the disabled person and partner, but, at the same time, was an intrusion of the domestic space and often meant a compromise of privacy and autonomy as a couple. According to Hannah, the non-disabled partner of Shaun, it was a "*no-win situation*":

> **Hannah:** *"I just think it's a no-win situation... I don't think you can be happy with either situation, you just have to choose whichever works...best and I think, for me, having a career is important... Moneywise I need to work to bring in some money, I couldn't live on Carers Allowance £50 a week... I think with the carer [PA] I did find that extremely difficult, having someone here and I'm quite a neat and tidy person, and the thought of someone, you 'know... even now I find that difficult because he doesn't do things exactly how I want it and I would like to be a little sergeant major and watch him! [Laughs]"*

Hannah's "*no-win situation*" is illustrative of the tensions which can arise when paid-for care is purchased. She positions the conflicting habits between her and Shaun's PA as very important. At the same time, having a PA enables her and Shaun to run their business, which allows Hannah to have a career and increase her earnings beyond that of Carers' Allowance. Thus, for Hannah, while using professional care alleviates the tensions of having to take the role of a carer which she finds very difficult, it brings with it other tensions and compromises and thus constitutes the "*Catch 22*" that both Hannah and Shaun describe.

Conclusions

Throughout this chapter I have explored the 'tensions' evident in disabled participants' intimate relationship narratives. Tensions or conflicts were found to be experienced in a variety of locations: through the relationship providing a *functional* space while also one in which participants tended to devalue themselves and be devalued by others; between a strong desire to be partnered (to avoid discrimination, prejudices and challenge ableist constructions) coupled with the relationship as a

problematic and, for some, harmful space; and lastly, tensions and conflicts were found within both non-professional and professional caring relationships. In this exploration, I have sought to reveal the role of disabled participants' actions and the forms of emotional work they undertook in order to manage and negotiate tensions. Crucially, throughout their stories disabled people cast *themselves* as active subjects, workers, managers, and facilitators and have shown that they carry out this important work in a variety of sites within the relationship. Not only does this challenge dominant constructions of disabled people which render them passive, unproductive and worthless, but it shows agency and resistance. Thus, in labelling and examining this emotional work (and the forms it can take), this chapter has provided fuller, more accurate and embodied descriptions of *experiencing* disability and impairment in the intimate relationship as a private space.

Importantly, data suggests that wider discourses of both disability and impairment shape disabled peoples' intimate relationships. Thus, the relationship is a social space and is not outside of the hierarchies, inequalities and oppression experienced by disabled people in public life. However, this is not how it is conceptualised by participants, many of whom positioned their relationships as symbols of their humanness, as serving important functions which make them 'complete' in opposition to wider constructions of disabled people as asexual and Other. Moreover, my analysis has discovered work and labours at sites where it has previously been overlooked, for example, as care receivers. Paradoxically, much of the skilled emotional work disabled participants said they carried out is highly valued within the labour market (Hochschild 1983), from which they are largely excluded (Barnes 1992; Abberley 2002). For example, people skills, effective communication,

empathy, understanding, and negotiating are particularly valued within service sectors and customer facing roles which dominate Western labour markets. Overall, work carried out was seldom mediated by a strict gender order. I suggest that this fits with the ambiguous and indistinct gender identities ascribed to disabled men and women in ableist cultures. For example, both male and female participants carried out typically feminised emotional work such as being cooperative, affirming, and passive within caring relationships. However, such feminised work is often seen as 'natural' for a woman, and 'exceptional' for a man. But, in certain spaces, typically gendered performances which affirmed dominant constructions of masculinity and femininity were offered; notably seen within the different strategies men and women employed to sexualise themselves, either in their own eyes, or in the eyes of others.

The routine 'work' required of the disabled identity in ableist cultures has been acknowledged in relation to public life within research from a disability perspective (good examples are Wong 2000; Church et al 2007). However, by utilising the concept of emotional work, which focuses on the types of work specific to private spaces, my analysis has revealed the mundane work required of and carried out by disabled people in their private, sexual, and intimate lives. Furthermore, my analysis contributes specifically to the dearth of literature relating to men's experiences of emotional work and the interactions of dominant masculinities and emotional work in private spaces. This has been lesser explored than the work of women, possibly because women have been found to carry out the majority of emotional work in such spaces (Strazdins 2000). The different types of (possibly, less powerful) masculinities enacted by or presented to disabled men challenges existing knowledge

of the male identity and power as privileged within the extent to which forms of emotional work are carried out by men (Hochschild 1983).

As Hochschild (1983) points out, the *cost* of such work should be considered. Clearly evident within participants' stories and in the analysis of their feelings, was the psycho-emotional disablism they experienced (Reeve 2002). Thus, despite being active 'emotional workers', it could be argued that this work actually reinforces their experiences of disablism and oppression. Goodley (2010: 93) suggests that responding to what he calls 'demanding publics' (fitting with and being defined by non-disabled peoples' assumptions) polices the emotional lives of disabled people – thus their emotional behaviours and actions must fit with depictions of gratefulness or victimhood, or risk being rejected if they show 'negative' emotions such as anger and resentment. Thus, Goodley (2010: 93) argues, disabled people must be 'good crips' in order to be accepted. As the stories of participants in this chapter have shown, being a 'good crip' is likely to be contradictory to emotional well-being and empowerment of the disabled person.

Chapter 6: The Impaired Body and Sexual Normativity

Introduction

The impaired body – which can be immobile, public, leaky, painful, abject and conventionally inadequate – is a powerful challenge to heteronormative sexuality. This is because the 'natural', moral, and compulsory sexual desires, pleasures and practices heteronormative sexuality requires marginalises all other 'non-normative' sexual interactions and bodies. Heteronormativity is defined by Holland et al (1998: 171) as 'the asymmetry, institutionalisation and regulatory power of heterosexual relations' (see also Lancaster 2003; Richardson 1996). According to this 'fucking ideology' (Shakespeare et al 1996: 97), successful sexual interactions are necessary, spontaneous, mutually satisfying, orgasmic, and take place through (heterosexual) penetration. As Tiefer (2001: 290) argues, 'if it's wet and hard and "works," it's normal; if it's not, it's not'. In this chapter I explore how the sexual pleasures, practices, and interactions of disabled people are shaped by both their anomalous embodiment (Shildrick 2009) and dominant discourses of heteronormative sexuality. My analysis problematises heteronormative sexuality specifically with reference to impaired bodies and determines how the 'hard physical realities' (Wendell 1996: 45) that may be experienced as a result of impairment, (for example, pain, spasms, incontinence, scarring, loss/lessened sensation, immobility, and weakness), interact with the gendered sexual identities and practices of disabled men and women.

My participants accepted, resisted, and negotiated dominant discourses of heteronormative sexuality, and while the reality of the impaired body was found for many to be a barrier to achieving normative gendered sexual practices, it was

simultaneously was a site where new possibilities, pleasures and methods (specific to the impaired body) could be discovered. Thus, for some, impairment could expand heterosex in locales where, for non-impaired bodies, the scope for transformation is limited (Jackson 1999; Shildrick 2009; Shakespeare 2000). However, this was often rarely how such sexual experiences were understood by many participants, who positioned their alternative sexual practices as Other. This finding supports the idea that, as Wilkerson (2002: 46) proposes, disabled people themselves render 'their sexualities incoherent, unrecognizable to others or perhaps even to themselves' and that this constitutes 'a clear instance of cultural attitudes profoundly diminishing sexual agency'.

Sexual Pleasure and Desire

This section explores participants' experiences and celebrations of sexual pleasure, considered by Tepper (2000: 283) as 'the missing discourse' within disabled sexual dialectics. I focus initially on participants' pleasure talk, before moving on to explore the ways in which the impaired body could resist and expand heteronormative sexual pleasure. Before sex was supposedly liberated in the 1960s through cultural, legal, and policy changes, its purpose was situated intransigently within the realms of reproduction. However, modern discursive constructions of sex are now centred resolutely on pleasure and desire. Sexological works, as stated in chapter two, have quantified, measured, and charted key stages within the human sexual experience (see also Kinsey 1948, 1953; Chesser 1950; Master's and Johnson's 1966). Such reductionist views locate sexual pleasure and desire firmly *within* the (normative) body. The absence of integral elements of 'successful' normative sexuality are pathologised and medicalised (Cacchioni 2007; Nicolson

and Burr 2003), and create dysfunctional bodies and sexualities (Tiefer 2001; Bullough 1994; Hawkes 1996). Sexological discourses therefore render the impaired body (and other bodies which do not fit its criteria) as abnormal and dysfunctional if they fall short of embodying sexual pleasure in mapped ways.

To experience sexual pleasure in the form of orgasm is, according to Masters and Johnson (1974), 'authentic, abiding satisfaction that makes us feel like complete human beings'. Thus, to orgasm is to be human. The orgasm has also become synonymous with health through the 'healthicisation of sex' (Cacchioni 2007). 'Healthy' bodies which orgasm in the right way (and at the right time) are rewarded with multiple believed health benefits: protection from heart disease and (prostate) cancer, the relief of depression, stress, anxiety and headaches, and an increase cardiovascular health (Komisaruk et al 2006). Impaired bodies, however, are not viewed as 'acceptable candidates' for sexual pleasure (Tepper 2000: 185), largely because they are presumed to be physiologically incapable. Much of this belief stems from the acute medicalisation of the impaired body: 'impairment *per se* is of central concern – its detection, avoidance, elimination, treatment and classification' (Thomas 2002: 40, original emphasis). This, as Tepper (2000: 285) suggests, combined with 'a biologically determinate viewpoint of sex as solely the province of reproduction, and 'reproduction solely the province of the fittest', has resulted in the sexual encounters and pleasures of disabled people being 'largely ignored, vilified, or exploited' (Tepper 2000: 284).

Pleasure Talk

All participants stated that they experienced what they identified to be sexual pleasure, and, for the most part, talked about sexual pleasures and desires relatively

freely and without the sexual shame that Wilkerson (2002) suggests is inherent within the erotophobia experienced by disenfranchised groups and sexual minorities. Younger female participants (under 30 years) were considerably reserved about pleasure, choosing 'safe' statements such as "*sex was great*" and "*I enjoy it*" but rarely elaborating on why and how. Older women showed more willingness to talk about the embodied pleasure they experienced:

> **Rhona:** *"Sex was brilliant, and we both enjoyed each other immensely*: *Intimacy, proximity, sensations, comedy, lack of control, feeling desired, being treated roughly and not as though I might break. It is also one of the few examples of when my body allows me a 'time-out', and I feel liberated. Done right, it is all pleasure and no pain."*

For some men, talk about pleasure often tied into hegemonic masculine sexual identities and ideas of performance:

> **Robert:** [favourite part of sex] *"When we both climax - Plus I do love boobs"*
>
> **Michael:** *"Well it's the greatest endorphin rush ever [sex]. It's a masculine role I can achieve."*
>
> **Tom:** *"I'm quite cave-mannish – [laughs] – especially when it's somebody I don't know; it's purely a hedonistic experience."*
>
> **Abram: "***Um … I loved touching her, I loved getting a blow job, I loved – I'd read various opinions on how it felt to get your balls sucked and I decided I – [laughs] –very much did like getting mine sucked. I'll always*

have that visual of [name of girl] there with my come [ejaculate] on her lips, which is a porn fantasy.**"**

While these statements are embedded within a hegemonic masculine performance, other men talked about enjoying typically 'feminised' sexual activities, such as foreplay, closeness and sensuality, without embarrassment:

Oliver: *"I definitely enjoyed sex but it wasn't the be all and end all, I enjoyed the foreplay more and the intimacy of being together."*

Terry: "*Well, I mean I most enjoy...well, one, actually looking – I mean, especially this is in terms of loving the person– is looking into their eyes when you reach a climax. The second one is really the after-bit of just lying with the person and just that sense of them – you know – when you can just lie together and feel that everything's stopped. They're the most enjoyable bits."*

Pete: *"I enjoy being together, alone without the kids or anyone else. I enjoy being without clothes alone with my wife. I enjoy getting undressed before having sex. The anticipation. I enjoy kissing. I enjoy being softly touched. I enjoy touching my wife. And just holding her afterwards, smelling her hair & kissing her neck or ear. I enjoy not trying to be someone I'm not. I enjoy oral sex. I enjoy mutual masturbation. I enjoy the obvious release it gives. I enjoy the tension then the release of my muscles."*

While non-disabled men may also talk about pleasure in such 'feminised' ways (see Seidler 1992), and can equally experience hegemonic masculinity as highly

oppressive, these alternative male accounts of pleasure suggest disabled men's *exclusion* from hegemonic masculine sexual identities can offer emancipation from, and an opportunity to negotiate, the oppressive gender binaries created and maintained through both heteronormativity and heterosexuality (see Shakespeare 1999; Gerschick and Miller 1995; Phillips 2010). As Shakespeare (1999: 63) contends, 'non-disabled men have things to learn from disabled men, and could profitably share insights into gender relations, sexuality and particularly issues of physicality and the body'. Appreciating intimacy, kissing, looking into a lover's eyes, and enjoying soft touch – and talking about it openly – shows resistance to hegemonic masculinities and sexual identities. Ostrander (2009: 15) suggests that impairment and masculine sex roles as conflicting can mean that, for disabled men, 'orgasms become less important than pleasing their sexual partner' (see also Vahldeck 1999). Therefore, 'disabled sexuality not only challenges the erotics of the body, but transforms the temporality of love making, leaving behind many myths found in normative sexuality' (Siebers 2008: 150). However, Guldin (2000: 236) suggests that such 'feminised' activities actually bolster conventional masculinities:

> 'For a man to be a patient, sensitive lover who is willing to go slowly and focus on the woman's entire body and on her pleasure may be seen as a more feminine model of sexuality. But if our cultural definition of being a "masculine man" is somewhat contingent on being able to sexually pleasure women, then this "feminine model" of sexuality actually increases masculinity.'

Being able to pleasure a woman is part of the rubric of modern masculinities (Seidler 1992). Thus, as Guldin (2000) proposes, learning methods of 'doing sex' which are

less focused on male pleasure, at the same time, offers men an equally central role in sex whereby they remain the pleasure provider. Thus taking part in 'feminised' activities reinforces this alternative, but still desirable, male sexual performance (see Holland et al 1998).

The construction of the orgasm within heteronormative scripts is as the 'natural outcome of sex – the only option for successful sex' (Cacchioni 2007: 306). Most of the spinal cord injured (SCI) participants in the sample (both men and women) no longer experienced orgasm in the way they had prior to injury. Lacking orgasm, something sexologists Masters and Johnson (1986) defined as a 'disease' called 'Anorgasmia', reinforces the 'primacy of orgasm for sexual pleasure' (Hawkes et al 1996: 69). Although not orgasming was explained by participants as a 'loss' (see Sakelloriou 2006; Tepper 1999), participants talked about alternative forms of sexual pleasure and feeling. Lucille expressed her experiences of no longer being able to orgasm in the conventional way:

> **Lucille:** "*Why would you want to have sex if you couldn't feel anything other than a weird nerve pain and why would someone want sex with a girl who couldn't orgasm? I can't feel any sensation that one would normally have but the way I feel does change in a way I can't describe. Teamed with my imagination it can be very pleasant, makes me feel sexy I guess, but I almost feel wrong for using it, like I shouldn't.*"

Feeling like 'she shouldn't' emphasises the way that people with acquired disability can feel asexualised following the transition to a disabled identity, but also that her newly 'queered' body (which no longer achieves pleasure in normative ways) is uncomfortable because it challenges culturally dominant preconceptions of what

(and where) pleasure and erogenous sensation should take place. Jenny, a 64 year old who experienced SCI at the age of 11, had a similar experience and said she seldom masturbated because she did not have the ability to orgasm. Thus, in conjunction with dominant discourses of pleasure, she had decided that without the obligatory orgasm masturbation was rendered meaningless. Phillip, who became disabled through a motorbike accident at age 35 (just three years before our interview took place), also said his sensations had changed:

> ***Phillip:*** *"It's very hard to describe actually, but you get... obviously you've lost outer sensation and the ability to climax, but it's amazing how strong the mind is and the enjoyment you get from, you 'know, the act, if you will, of sex. So... that has diminished... it's diminished the kind of... I guess the, it's not enjoyment as such because I love having sex, but it's the... there's... I could say there's something missing in it, actually. I mean you get... the best way of describing it is you get this sort of sensation; you don't ejaculate but you kind of get sensations of orgasm but it's not a full-on orgasm so you get sensations and those sensations are great so there is a ... erm, you know... erm, you get a sensation of climaxing but you don't... but it's not as strong as it was before".*

Phillip's assertion of something being "*missing*" supports Tepper's (2000: 289) research with SCI males which found that most males described post-injury pleasure as "*not the same*". While Phillip did report *increased* sensation outside of standardised erogenous zones (e.g. his arms), and said that this made him more sensitive to touch "*in a nice way*", he felt it wasn't a replacement for the loss of genital sensation. Tepper suggests (2001: 289) that this originates from 'the absence

of quality sexuality education combined with learning about sex primarily from having genital intercourse' (see chapter four) and thus this leads 'to sexuality embodied in the genitals and cognitively focused on perfect performance with the goal of orgasm'. Phillip's account also shows the way in which participants (particularly those with acquired disability) often found sexual pleasures difficult to describe, suggesting that there's little alternative language or lexicon through which to verbalise (hetero)sexual pleasure outside of 'climax' and 'orgasm'. Additionally, even these can also be hard to define as 'climax' and 'orgasm' are, in a sense, descriptions of 'events' rather than feelings. As Jackson suggests (1999: 171), heterosexual language is 'restricted to very predictable conventions such as terminology from *Mills and Boon* novels and pornography'.

Queering Pleasure: Resisting and Expanding Normative Pleasures

One participant with SCI, Shaun, a 33 year old who became a wheelchair user in an accident at the age of 10, *could* orgasm through stimulation of conventional erogenous zones, but took advantage of the ways in which his newly revised body facilitated sexual pleasure. He said his shoulders (just below the point of injury) were incredibly sensitive to touch and that he and his wife Hannah had incorporated this pleasure into their sex life:

> **Shaun:** *"I have very sensitive areas on my shoulders and... 'cos that's where I was injured so that's kind of a natural thing... so it's nice just for the touching side of things, really."*
>
> **Hannah:** *"Yeah, I remember the first time, because I didn't know that about spinal injury and I was stroking Shaun's shoulder and he was like*

"wow!" [Collective laughs] I was like, "What?!" I think I must have stroked it for an hour!"

Shaun: *"She gets bored after a couple of minutes now! [Laughs]"*

Hannah: *"So that was an eye opener, that wow, so... I think you could get to the stage of having an orgasm through touching above the injury, which is amazing really."*

Thus, the impaired body as that which (for some) may struggle to reach orgasm challenges the very essence of heteronormative sexual pleasure and both disturbs and shifts sexual embodied norms (Ostrander 2009). Shaun and Hannah's experiences show the possibilities of pleasure, through exploration, that impairment can produce (Parker and Yau 2011). Similarly, Pete, who is congenitally disabled, reported his muscle spasms as being very pleasurable and adding to his overall enjoyment:

Pete: *"My legs, stomach, bottom, feet, toes & (arms not so much) have spasms (muscles get real hard) when I'm in the throws making love, increasing the more excited/aroused I get. Once I've climaxed/ejaculated these muscles & joints quite quickly relax – I like that feeling of tiredness & relaxedness whilst in the knowledge I've pleased my wife. I can't walk for a while after."*

Pete's additional embodied pleasure that his palsied muscles bring forcefully challenge conceptualisations of the impaired body as an asexual and inadequate site. Such findings support queered approaches to the impaired body which define it as a space of vivacity and production (Overboe 2007a), that which can 'expand and envelope in exciting ways' (Goodley 2010: 158).

Normative sexual practices and pleasures are positioned in sexological accounts to occur in sequence, 'building' up to the end goal of climax and orgasm. In addition to different *forms* of pleasure the impaired body could create, the body was also positioned by participants as unpredictable and unruly regarding orgasm. Gemma, a lesbian, talked about the way her impairment episodically affected her ability to orgasm and labelled her body "*dysfunctional*" at such times. This illustrates that heteronormativity and goal-orientated orgasm-focused pleasure is not the preserve of the heterosexual identities. However, a strategy to manage an unruly sexual body was to displace, decentre or demote the orgasm within the sexual experience. Hannah and Shaun told a story of how they'd struggled extensively regarding the 'need' to orgasm as a marker of "*good sex*". The couple's narrative was based around the ways in which they had successfully dealt with this pressure, which could impact upon Shaun's ability to sustain an erection. Shaun said they were trying to expand their views around sexuality, and that this brought them less pressure and more pleasure:

> **Shaun:** *"...Stereotypical views of how sex should be. This is something we found quite... you're very goal orientated, sex is like 'well she's got to come and he's gotta come or the other way around or... you 'know, you've got to have intercourse and that's part of sex, you 'know, there's a set... wham bam thank you maam kind of steps. [...]I think that was just adding to it [the pressure] and we were getting to a point where, at the end of this period of an hour of trying, there was disappointment because it wasn't what we expected it to be... But over the last 5 or 6 months it's kind of, yeah, if you lose that goal orientation kind of thing and there's no*

pressure... [...] we have a very strong relationship and good sex would be the icing on the cake, if you like... but we get as much out of cuddling and being close to each other as we do out of sex, I think. It's... I guess some people may look at that and go "you're just a couple of freaks" but the sex is nice and it's good and it does make you feel that... that close, that little bit more intimate, it's not the be all and end all. [An orgasm] it's nice, obviously, but I get as much enjoyment from other things... from just being close to Hannah and just maybe being touched and being stroked... In fact, I probably get as much satisfaction out of seeing Hannah have pleasure than I do from actually getting it myself, which you 'know, [to Hannah] you should be whooping about surely?! [Collective laughs] That's just the way I seem to have developed in this relationship, it just seems to be that way and I don't necessarily need to have an orgasm or whatever to, to enjoy that intimate time together."

Thus for Hannah and Shaun, resisting heteronormativity and its narrow prescriptions, particularly in relation to the orgasm, was the route to *regaining* pleasure (in various ways) and renewing the enjoyment of their sexual life. The assertion of the "*freak*" nature of their enjoyment of cuddling and intimacy expands phallocentric sexuality to become that which, as Sakellariou (2006: 102) states, can be 'closely connected with emotional closeness and pleasure, which can be achieved through any range of practices'. Shakespeare (2000: 164) questions whether disabled people should fight to be included within a mainstream sexual culture which largely overlooks intimacy and sensuality and propagates notions of the 'Cosmo conspiracy of great sex', the (false) idea that most people are having great sex, all of the time. Thus as Shaun and

Helen's experiences above illustrate, not only can the pressure of such conspiracies be so overwhelming that they end up being counter-productive, and in their case, resisted, but the very inability of Shaun's body to meet such a conspiracy simultaneously offers him a means through which to resist it. Thus, in this sense, for some, impairment may offer an escape from the oppressiveness of heteronormative sexual practice.

Another means through which normative pleasures were expanded was through the acts of sexual *fantasy* and obtaining pleasure through *visual* means – thus shifting pleasures away from 'the fleshy' and corporeal bodily sensations emphasised through heteronormative discourse. For Lucille, a married woman with acquired SCI, fantasising offered freedom from the way she felt her physical body impacted upon her sexual pleasure and practice:

> **Lucille:** *"I think of scenarios in my head when I am in bed, things I wished could happen, I suppose what I am saying is I fantasise, usually about a particular man I like. I like it that I get some me time when I am in bed and I can let my imagination run free and I can be who I want to be.... I think for someone in my situation imagination has a big role to play, the mind is the most erotic organ as far as I am concerned [...] Sometimes the thought is better than the doing. That's a terrible thing to think."*

Similarly, Hayley, 32, said that "*a good imagination*" was an alternative means to bodily pleasure because she couldn't physically masturbate in the conventional way. Sally, a 21 year old self-identified virgin also said she enjoyed sexual fantasising as a means of pleasure, but expressed that she was worried this was "*all she would ever*

have". While women were coy about fantasising (never revealing the content of fantasies), one male who said he used fantasy regularly was more forthcoming with detail, showing once again the typically gendered nature of sex talk, Bob said: *"My mind drifts in fantasy. I've had an interest in women's buttocks and often imagine a girl bending over my knee, pulling her skirt up, slowly pulling her knickers down and fondling her buttocks and thighs."*

Shakespeare (1996: 74) argues that 'many disabled people end up by disassociating from their body – not owning it because it causes trouble or because someone else cares for it'. However, some of my participants have disassociated with their fleshy bodies in order to reaffirm the imagination as an erogenous zone in itself. This ability, regardless of its deficient status within normative notions of the sexually able body, shows once again how disabled sexualities and impaired bodies can expand sexual normativity which is, unimaginatively, defined to only take place only through the flesh. Pleasure was also re-inscribed as *visual*. Despite the fact that Graham *could* experience masturbation, orgasm and ejaculation alone in private, for a variety of reasons he never experienced these pleasures with another person. Most of his narrative was centred on his inability to 'consummate' any of his relationships and he defined his sexuality as: *"sex for me isn't touching a woman, it's looking at her".* In order to satiate his desire to look at women as a form of sexual pleasure, Graham had started posing as a professional glamour photographer, inviting (unknowing) prospective models into his home to photograph them. Such practices show how non-normative pleasures can sometimes involve entering into 'deviant' territories.

However, while fantasy-based and visual pleasures serve to develop predictable corporeal notions of pleasure, the participants who experienced such pleasures defined them as 'not the same'. Further to this, Graham's 'abnormal' pleasures led to him having several traumatic encounters with sex workers where he forced himself to try and have 'sex' in 'normal' ways. As this wasn't possible, his feelings of failure caused him to pathologise his own behaviour. He spent thousands of pounds on sex surrogacy and sex therapy which put him into considerable debt. Upon seeing his GP, Graham was subjected to "*two years of referrals through the health service*" and was even referred to what he identified as a well-known clinic for "*weirdoes... paedophiles, serious, serious criminals*". Graham's experiences not only show how non-normative pleasures can be pathologised through medical discourse, but that his *self*-regulation of his *own* sexuality was 'complicit' in such pathologisation (Foucault 1976).

The Impaired Body

According to Goodley (2011: 41), the impaired body is 'a sexually challenging idea'. Moving beyond early disability studies' somatophobia (Crow, 1996; Hughes & Paterson, 1997; Williams 1999; Meekosha 1998; Thomas 1999), in this section I consider the corporeal in order to understand how the embodiment of impairment interacts with disabled participants' performances of a sexual self. Initially, I examine participants' accounts of body image, and the ways in which they managed their deviation from normative aesthetic embodiment. Later, I explore what participants said about bodily function and their negotiations of the practicalities required of the impaired sexual body.

Body Image

Many participants made reference to their body image and bodily hatred within their sexual stories. The impaired body's departure from the idealised beauty aesthetics required of women, and more increasingly men, in Western cultures affirms its status as wretched and abject. Some participants' self-hate was fuelled by the way their bodies deviated from the embodied 'norm'; scarring, muscle wastage, 'deformity', and weight gain (due to inactivity) firmly underscored the dogma of the 'monstrous' impaired body (Shildrick 2002). Disabled men compared their bodies to the (male) body beautiful – which is muscular (participants talked frequently about 'six packs'), strong, perfected, and achieved. However, while not meeting such high bodily expectations caused feelings of disgust and self-hate for some male participants, for most it was an area of their sexual story where talk was most pragmatic, practical, and matter-of-fact:

Robert: *"My body is not Arnold Schwarz thingies but I can live with that!"*

Tom: *"...I'm no Brad Pitt yeah, but I'm no Quasimodo!"*

This matter-of-fact talk may result from 'body talk' being an activity culturally less available to men than women. Thus, revealing body insecurities may have been avoided because it would be seen to disrupt hegemonic performances of masculinity. Other men told success stories of 'coming to terms' with body image, explaining their bodily acceptance as a journey and achievement; that working on changing their perception of their bodies enabled the reclamation of a positive body image:

Tom: *"We live in a society where we're constantly projecting the idea of a perfect self, erm [sighs] and sometimes it's very difficult to reject that*

and create your own identity and your own self ... but of course I do, like, you look at people like David Beckham and you look at how he's idealised in terms of his sporting and physical prowess and then you realise that you can't do any of those things that society perceives as being sexually good or sexy or beautiful, and then it, it kind of triggers a thought process that in the end that – what you do is work through that, and come to terms with that you are who you are and that you are beautiful."

Thus, men like Tom showed what Ostrander (2009: 16) suggests disabled women experience: the development of 'body competence' which 'which provides women with more confidence to engage in sexual activities'. Or, as Guldin (2000: 234) suggests, disabled people can 'negate, displace, or supersede' their feelings about non-normative embodiment: 'what is constructed - if not a sexy body - is nonetheless a sexy being'.

Importantly, female participants seldom spoke of equivalent journeys through which they could occupy or exhibit the power to reject normative bodily aesthetics and narrow prescriptions of cultural attractiveness. Bartky (1990: 40) suggests that women are made to feel shame within femininity; that femininity constitutes an 'infatuation with an inferiorised body' against which women will always feel inadequate. Thus, as Wilkerson (2002: 46) suggests, 'heterosexual women are made, and make themselves, complicit in hierarchies that systematically disadvantage them'. My findings here illustrate that disabled women are not an exception within this system. However, body worries did surface in men's stories when speaking about sexual identities, and many expressed great concern that prospective sexual

partners would make comparisons between normative 'perfect' and impaired 'different' bodies, and thus would feel 'cheated' at this bodily divergence. Thus "*not looking the same*" (as the normative body) and feeling "*unsexy*" featured continuously in the majority of participants' stories. Some female participants said that the times they felt sexiest were when consuming alcohol or when sexiness was affirmed by a male partner; and while both men and women spoke about their 'relationship' with "*the mirror*" when talking about body image, it was women who talked of hiding or deflecting bodily difference through the use of clothing and other means. In addition, female participants tended to relate to their bodies in a more descriptive and vivid way, often 'listing' and thus 'revealing' the body 'abnormalities' which brought them the most displeasure:

> **Lucille:** *"My body – hideous, unattractive, un-toned, feeling – loss of any sensation."*
>
> **Sally:** *"I hate, hate, HATE my body!! My lower spine is curved, so I'm really short in the body & a-symmetrical...which means clothes (the few that fit) actually look really awkward & don't hang well which makes me look even worse. Because my condition is muscle wasting, the tops of my legs are like jelly & from the knee down - really skinny so I never wear skirts/dresses - usually trousers with long boots. Equally, the tops of my arms are jelly like & my wrists are really skinny, bony & as I'll always remember one lad at school saying - spider like! Horrible! I have a horrible serpent like, skinny neck & no shoulder muscle. My right foot turns in & looks like a club foot (despite 2 very painful operations) erm... the list goes on. I'm currently paying privately for fixed braces & am*

hopefully having a boob job in the summer as I literally have no boobs - 12 year old boys have bigger boobs than me! I'm trying to fix the things I can - like teeth, to try & improve whatever I can."

Talking about the body through such descriptive language and committing to bodily projects to 'fix' and 'make the best of the body' through clothes or more permanent bodily work are cultural practices also shared by non-disabled women. Such practices not only reveal the ways in which women remain defined and valued through their material body, but are symptomatic of neo-liberal individualist discourses prevalent in Western society where the body comes to have exchange value and hence is a project upon which to work (Rose 1998). Negative feelings about the material body were also found, for some, to affect sexual pleasures:

Pete: "*This inability to relax enough to climax was becoming an issue. My wife would finish her orgasm and would have to stop before I climaxed as she was so tired, I still couldn't ejaculate. We'd be at it for hours. It was so frustrating and I was worried she was going to run a mile. She went to the newsagent and bought some porn magazines. I asked her why she'd bought them (feeling a little threatened). She said "I want you to relax about sex, it's nothing to be scared of, we're learning together. We'll take our time together". We talked about the [porn] photos and I discovered that I may move differently to an able-bodied man but I looked the same naked (have all the same things/shapes/sizes in all the same places). There were photos of men with full erections - my wife said "there see, you are no different to any other man!"*"

Pete's experience shows how crucial bodily appearance – and proximity to the normative body – can be towards the acquirement heteronormative sexual pleasures. Likewise, other participants said that in order to manage this they tried to hide non-normative ('deformed') parts of their body from sexual partners and even themselves during sexual encounters. For example, Jane said that she doesn't enjoy sex as much when she can see her feet, which are a non-normative shape and scarred due to her impairment (and surgery). Although she says that her partner likes her feet, Jane said she only has sex in positions where her feet are out of her eye line; alternatively she will keep her eyes closed. Similarly, Oliver told how he routinely wears long sleeves during sex so as not to expose his "*thin arms*" (due to muscle degeneration). Helen told how she had gone to great lengths to hide a part of her body of which she felt very self-conscious. These attempts at hiding meant she couldn't "*let myself go during sex",* she said, *"I've always got to worry*". However, her partner later 'discovered' what she had been hiding:

> **Helen:** *"My bum's kind of got this, like, indent on it...it sounds really gross. Erm and I always try and hide it and I always think I do and then the other week he said to me, "Do you know you've got an indent on your bum?" I was like [looks exasperated]. I don't even know, like, what I said... I was like, "How do you know?!" I was gutted, I thought I'd hidden it, but obviously I hadn't, obviously he'd seen it one day when the light was on or something."*

Helen considers her "*indent*" unacceptable within the rubric of the normative body: 'the body from which all other bodies are judged' (Davy 2010: 186). Helen's and others' experiences of hiding suggests that both for themselves and for others (their

partners), disabled people fear that their departure from bodily normalcy can be a basis for rejection, and thus the need to 'pass', (and all of the work which goes with this), remains.

Functions and Practicality

For many participants tiredness, fatigue and pain, had significant impact upon the ability to engage in sexual encounters. For example, Gemma, a lesbian with an immunity disorder that causes extreme fatigue, said that both humour and negotiation of reciprocal pleasure were fundamental at times where she was exhausted:

> **Gemma:** *"I mean it's something we negotiate, you know, I'm quite comfortable just saying "Oh look, I'm really knackered" you know "How about a quick orgasm, help me go to sleep" and she'll go "Alright then". I mean, we sort of laugh about it, she goes "Oh you'll owe me, I'll expect one in the morning" sort of, you know... I mean I think it's just sort of about being grownups really, it's…and having a sense of humour about it."*

Gemma and her partner's willingness to negotiate pleasurable equitable exchanges reinforces that some lesbian women may be liberated from heteronormative gender norms and oppressive heterosexual hegemonies which situate pleasure as a necessarily simultaneous 'mutual' exchange (though one where the terms of the exchange are usually mediated by male sex discourses). However, for others, tiredness was very frustrating and could encroach upon performance of sexuality:

> **Lucille:** "*Despite my suggestive comments to [husband] in the morning, I fell asleep almost immediately. In my head I've got so much energy but the sad truth is I just get so tired sometimes that my body can't keep up with my head*."

In this account, Lucille positions her sexual mind and body as separate entities – thus her rational (sexual) mind is functional, while her unruly physical body is unmanageable. Such Cartesian thought, the mind and body as a divided entity (Descartes 1974), was a common theme in participants' stories, in which the impaired body was positioned as disruptive to an otherwise 'normal' sexual self. Pain impacted negatively upon sexual pleasure and practices, and often, affected whether sexual activity took place at all, a finding which echoes that of other research on pain and sexuality (see McCormick 1999). Helen said that severe and progressive hip pain now means she can no longer simply be lifted on to the bed by her partner and that transferring from her wheelchair to the bed is now a more complex process which takes considerable time (thus affecting how she feels when reaching bed). Lucille had a similar situation and found humour a useful strategy for dealing with this situation: *"Must be fab to get into bed and out of bed yourself... If I ever wanted an affair I'd have to send my lover to lifting and handling classes first!"* Pete said that despite the pain in his legs and hips affecting his enjoyment of sex, it is his wife's fear of hurting *him* that has the most negative influence. Thus, even if the disabled person can 'work through pain', a partner's fear of worsening pain and causing harm can be distracting for both partners. This contradicts Scarry's (1985) positioning of pain as that which can't be shared nor confirmed by others and suggests that effective pain-management is integral towards maintaining sexual life for *both* partners.

Sex and incontinence was not something participants discussed readily, and very few made reference to this factor, even though many had impairments which made them singly or doubly incontinent. This mirrors the lack of attention paid to incontinence within disability and sexuality literature – despite it being, according to Morris (1989: 91) 'one of, if not the most, inhibiting things about paralysis when it comes to having a sexual relationship'. Morris (1989) found that for many of the disabled women in her research, incontinence was enough to stop women looking for or having a sexual relationship at all. Culturally, incontinence is associated with babies, infants and older people (Lupton 1996) and thus is seldom acknowledged within disability studies for fear of reaffirming discourses of infantilisation. In more recent research, Leibowitz (2005: 92), who also carried out research with disabled women, found that her informants' fear of incontinence 'affected the ability to enjoy sexual encounters, their conceptualizations of themselves as sexual beings, and their willingness to meet new men and/or resume sexual activity after injury'. Another of my participants, Lucille, said she was conscious of her non-urethral catheter during sex, that she knew it was there, and that she worried about keeping it out of the way so it wouldn't interfere during intercourse (a complicated process which involved a lot tape). However, other female participants in the research adopted a pragmatic approach to incontinence. For example, Jenny and Gemma said that they had (accidentally) urinated on sexual partners during sex as a result of their incontinence, and that while this wasn't ideal (and could be particularly awkward with new partners), humour was a key strategy in managing this issue: "*Like, pissing yourself is not a particularly attractive quality, let's be honest [laughs]*". However, while embarrassment was managed, incontinence could still have a practical impact. Jenny said that her incontinence meant she had to completely empty her bladder and

bowels as much as possible prior to sex, and carrying out this task (which minimised the chances of 'accidents'), affected her and her partner's ability to engage in spontaneous sex. Others considered catheters to be painful and a hindrance to sexual activity. Pete found having a (temporary) catheter an excruciating experience and said that this pain became more intense when he had an erection. He changed to a supra-pubic catheter (a catheter inserted via the abdominal wall rather than through the urethra), but sex was still painful and so he and his wife refrained from sex during this time. Likewise, sheaths, a body-worn device resembling a condom which fits over the penis and allows for urine to be collected in a bag, added considerably to the preparation which needed to take place before sex.

Thus the reality of having a body with impairment was found to impact upon the unspoken 'practicalities of having (normative) sex': preparing the body for sex, setting the correct environment for romantic sexual scripts, and the carrying out of post-sex bodily work (e.g. 'cleaning up'). Much of this work was routinely carried out by the (non-disabled) partner. For Hannah and Shaun, the need to prepare Shaun for sex was a key feature of the couple's sexual story and the level of extra 'work' required by Hannah could be a point of tension in their relationship:

> **Hannah:** *"Because Shaun wears, like a sheath [for urine], I often feel like I'm too tired to prepare to have sex and it's something that we really... Well, usually I have to take the condom off [urine sheath], give it a wash... Have a shower; maybe brush your teeth... I'm a bit anal about that [Laughs]... erm, that's probably about it."*
>
> **Shaun:** *"But then it's no different really because you'd expect that of an able-bodied partner."*

Hannah: *"You would, but the difference being that I have to help you do that...whereas..."*

Shaun: *"You have to help me do it, yeah."*

Hannah: "*An able-bodied person would do it themselves, erm..."*

Here, Hannah talks about having to suddenly switch roles from carer (providing preparation for sex) to lover, and said that this impacted significantly on her arousal ("*I found I wasn't getting wet [aroused]*") and that this had a major bearing on the sex which followed. However, the couple expressed that such barriers were not insurmountable and that they were trying to find ways around them:

Hannah: *But we're trying to find ways... sometimes I think 'oh, I must be lazy that I don't want to take off the condom' [urine sheath], give it a wash and then put it back on, but we're trying to find ways... that maybe the carer comes in and helps Shaun have a shower to kind of...so that I only have to put it on afterwards or just stuff... the killjoy stuff, to kind of reduce that, or we do it [sex] on shower days, that we have a shower together and kind of do it [sex] as part and parcel of that so it's not, not so much of a focus..."*

Showing that strategies can be put in place to deal with issues of incontinence, Hannah cites the couple's PA as having a role to play in preparing Shaun's body for sex. However, at the same time, solving the issue this way means relying on a third person (the PA) and therefore restricts sex to certain times and spaces. 'Cleaning up' after sex was also referred to as difficult to manage, and particularly awkward, embarrassing – or as one participant stated – "*traumatic*":

> **Lucille:** *"It's not the greatest way to do things is it, for a man – to have sex and then wash your partner as she is unable to do it herself. Then the incidental things like not messing the sheets because a PA is in to help transfer the next day, not getting messy yourself because you can't just hop in the shower – that's a two person job as well."*

Lucille's point about not "*messing up the sheets*" echoes the impact of a PA involvement with a couple. For Lucille, PAs coming in to assist with washing and dressing in the morning also meant dealing with embarrassment of them knowing she'd had sex the night before. She also implies that the required practicalities of her husband having to "*clean her up*" after sex affects her feminine identity. However, Terry's strategy around this situation was to incorporate such bodily 'duties' into the sexual experience overall:

> **Terry:** "*Yeah, I think probably the bit I don't like is the fact that because I have to rely on someone else to assist, it means that they have to clean up everything afterwards. It's like, at first that was the most traumatic thing. But then with girlfriends it kind of ... you were able to incorporate that into the experience. So for example, afterwards, if you had the time, you could then take a bath or whatever together, and it'd be nice to experience that as well. It can become part of something that isn't just a practicality... [but] part of the romance as well."*

Terry's experience of embodying and being creative with the practical duties required of the impaired body during sexual life is a positive route towards shifting such assistance (which he first defined as "*traumatic*") to "*part of the romance*". However,

as Terry point out, this strategy is likely to be restricted to intimate relationships and romantic contexts (rather than casual ones) and where a partner is obliging.

'Meeting' the Requirements of Heteronormative Sexuality

In this final section, my analysis reveals participants' attempts to 'meet' the physical, gendered, penetrative, and spontaneous requirements of heteronormative sexuality. The bodily aspect of impairment which participants cited as most affecting their sexual practices was restricted movement. The sample represented a wide range of impairment severity, but most participants felt that immobility 'constrained' the *type* of sexual expression they wanted to perform (see Taleporos 2001; Taleporos & McCabe 2001, 2002a). Restricted movement was found to mediate a range of practices related to heterosex: sexual positions, gendered sex roles, penetration, and spontaneity. Thus the very 'physicality' of heterosex was central to the collective disabled sexual story.

Physicality and Gendered Sex Roles

Sex was understood by most to be a highly physical activity which required significant bodily movement and control. Lucille, who acquired disability through SCI, said that the sheer physicality of sex made her feel "*completely asexual*":

> **Lucille:** "*That I can't move is a problem and so many other things that affect my ability to enjoy sex as it should be enjoyed"*.

Similarly, Helen and Rhona, both wheelchair users, said they worried about what they physically couldn't do within sex. For example, Helen said: "*I can't do the things a walking person can do... you obviously can't do things that, there's always a few lacking things... you can't do what a normal person would do"*. Thus, these (and

other) women's accounts show that they consider themselves as not meeting 'normal' physical expectations of heteronormative sex (which non-disabled women are assumed to unquestionably meet), and thus relate to sex as it *should* be enjoyed. Other participants made frequent references to not being able to 'do' certain sexual positions, or being limited in what they could offer in terms of sexual positions because of issues of bodily flexibility and strength. Participants continuously used the non-disabled 'sexually able' body as a marker of normalcy regarding both sexual positions and practices, and through their stories made the case for how their bodies 'deviated' from this norm. However, some male participants recognised that many non-disabled people may not reach such expectations; as Michael said, "*I couldn't perform certain sexual acts, the crazy ones in the karma sutra, but I don't think anyone does*". Nevertheless, Michael also said that his high degree of "*manoeuvrability*" (his relatively 'mild' impairment) means he is "*fully functional*" and thus a "*proper full man*" showing that, as with other male participants, men often continue to define themselves through – and enact – hegemonic masculinities. This fits with existing notions that people with more severe impairments have lower sexual self-esteem that those with milder impairments (McCabe and Taleporos 2003; Hassouneh-Phillips and McNeff 2005). Such examples also highlight the competing demands of disability and masculinity, which are 'complex phenomena that are negotiated and renegotiated, day to day, in diverse social, political, and interpersonal contexts' (Phillips 2010: 120).

For both male and female participants, issues of movement were heavily related to the gendered roles they adopted during sexual interactions. The majority felt they had to adopt a different role during sex to the one they wanted. For example, many of

the men in the sample couldn't adopt the customary (gendered) practice of taking a 'dominant' role (e.g. being on top of a woman during intercourse) due to their impairment. For some, again, this was met with pragmatism, and others, humour (Tom joked that he was a "*lie-back-and-think-of-England type of man*"). However, for most others it was felt to seriously undermine masculine sexual identity:

> **Pete:** *"I'm not the one who's in control as, I feel, a man ought to be during intercourse. Maybe if I was the female in the relationship I wouldn't feel such a failure as I do in my role as a man."*

Pete's account explicitly reveals dominant gendered sexual roles in typical heterosexist scripts: as a man who cannot take what he defines as an active role in sex, he has failed. His assertion that if he were a disabled woman he wouldn't be as much of a failure maintains dominant ideas of women's sexual passivity and submissiveness during intercourse. Notably, this wasn't at all the way many disabled women felt; they equally felt inadequate in comparison to the constructed norm (discussed later). Male participants were also concerned that this 'unmasculine' woman-on-top position impacted negatively on their sexual partners, thus it compromised their masculine role to the misfortune of their partners. Most male participants also referred to the *type* of sex they offered; for example, a few made reference to not being able to have 'rough' or 'hard' sex:

> **Kadeem:** *"Like she would have to be on top... girls like guy on top and getting banged, like hard sex... I would love to be on top of a girl and fuck her hard... I used to talk to that girl about this and she said we can try things, but I knew it would be too difficult..."*

Pete: "*She's never asked me but what if she'd like to make love differently? What if she'd like it rough sometimes?"*

"*Getting banged*", "*fuck her hard*" and "*liking it rough*" are descriptions of sex embedded in hegemonic masculinity and normative heterosexist scripts where a dominant male performance is central. These descriptions are heavily advocated through pornography and popular culture. Many men in the sample also referred to great frustration of their impairment causing a reliance on (female) partners for the pace and control of intercourse. Some positioned this 'lack of control' as problematic to their (male) sexual autonomy and agency:

Robert: *"I can kiss, caress, but not thrust – girlfriend one got lazy and reverted to doing 'stuff' rather than the effort at times, like hands on each other to climax but not intercourse, girlfriend two was awesome with it [penetrative sex], girlfriend three was just not that sexual I think so it was less disability and more lower sex drive".*

Robert's (somewhat sexist) account's of his previous girlfriends shows how the disabled person can lose agency within sexual interactions and is, as in other areas of their life, reliant on someone else for assistance. However, Terry said that a lover had suggested his inability to control the pace of penetration made sex 'better':

Terry: *"...I found out for certain girls, they've enjoyed it more because they've always wanted to go on top and their [previous non-disabled] partners haven't wanted them to go on top. [...]I remember one girl said to me she actually felt it was better to have sex with a disabled person than a non-disabled person; she just said because your positions are limited and because you can't move around as much as a non-disabled*

person it means that she can get the optimal position for her and the most enjoyable for her. So that was kind of – that was kind of a boost, really. [...] But, as I said, you know – there was a time when I thought 'oh, I can only do it on a bed' and then, you know, through experimenting, the wheelchair became a viable option as well. So... you find new experiences... new ways of exploring..."

Terry's partner's assertion that sex with a disabled man is 'better' because it gave her more control regarding position and pace (and thus more pleasure) adds emphasis once again to the notion that impairment can expand the conventions of heteronormativity; in this case, through challenging the naturalised gendered hierarchies of heterosex, or as Jackson (1999: 171) articulates, 'the (active) male and (passive) female dichotomy'. Consequentially, some participants in the sample said that the 'natural' strategy to not being able to move one's body is to verbalise needs and wants during sexual interactions. Participants talked about this verbalisation in different ways – for some it bought pleasure, but for most it was frustrating, tiresome, and a burden to the sexual role they wanted to perform. In addition, the act of verbalising was found to have different meanings for male and female participants:

Robert: *"I have to verbalise a lot if I want her to move me or her to come closer... Then I verbalise how I feel and [can] initiate positions I flourish in"*

Tom*:* **"***Erm, it's like negotiating a different role, if you want to move in a certain way you have to ask the other person to move [you]."*

Lucille: *"I'd love to be able to start things without verbally communicating that that's what I want! I'd really like to experiment a lot*

more as well but I don't know, it's hard to communicate that, discussing everything first makes things seem dirty sometimes and it ends up that I don't say a thing, I just have all these thoughts circulating in my head."

Rhona: "*It just isn't the same when you have to talk everything through."*

These accounts suggest that verbalising sexual needs and/or wants is a process which is culturally more available to and acceptable for men than women. Lucille's assertion that speaking aloud about "*what she wants*" makes her feel "*dirty*" fits with discourses of inappropriateness and passivity which constrict female sexualities and desires. More importantly, Lucille shows that the risk of disrupting a suitable gendered performance causes her to say nothing at all. Rhona's assertion that verbalising 'just isn't the same' once again shows how deviating from heteronormative scripts is largely interpreted as failure. Thus, the inadequacy of verbalisation as an alternative to movement simultaneously reinforces that heterosex is ultimately always embodied and thus 'of the flesh' (Tiefer 2001).

Many women said that their impairment impacted upon the more active role they would like to have within sexual relations, thus challenging dominant gendered sexual norms; for example, Lucille said, "*I can't move – who is going to want sex with a girl who can't move?"* As Ostrander (2009: 16) found, 'women shared the concerns [of disabled males] about role of disabling perspectives on their sexual pursuits'. Lucille felt that her acquired disability meant that she could no longer be an instigator of sex with her husband in the way she had been before her accident. She said her attempts to instigate "*a fumble*" result in "*me clumsily hitting him somewhere he'd rather not be hit! It's not always like that, but sometimes it's incredibly*

frustrating". Lucille also said that her acquired impairment made her less sexually "*assertive*". She told a story of how she'd bought a vibrator for her husband to use on her during sex, but as it "*did nothing for him*" they stopped using it and she felt she couldn't "*press the issue*". Rhona had similar feelings:

> **Rhona:** *"Yes, I would love to be able to initiate, and take control more. It is incredibly frustrating not being able to do things for your partner that you know he would enjoy. It's also annoying that he has to do all the work, although he seemed to think it was more than worth it… It means I am much less actively involved than I would like to be."*

Concerns about partners doing "*all the work*", as Rhona puts it, was related to general anxiety around a partner's sexual enjoyment and pleasure, affirming once again the privileged status of mutual pleasures with heterosex. Helen also said she wished she could do "*more things*" for her fiancé during sex, and that her inability to carry out certain sexual practices made her feel "*bad for him, I feel bad for him rather than me*". Hannah, non-disabled wife of Shaun, talked in detail about gendered sex roles. Hannah had experienced "*negative sexual experiences with previous partners"* and did not feel comfortable taking the 'dominant' role (of being on top of Shaun) during intercourse:

> **Shaun:** *"I think you come into it and you think, how is this going to work? It's gonna be Hannah on top all the time... but again that's something that with the Intimate Rider, it's something that there are ways and means, you just have to be much more imaginative really."*

> **Hannah:** *"Yeah, I think that was something that I was worried about, about having to be in charge, because of my bad experiences I really wanted Shaun to be [in charge] and I think that, with the Intimate Rider and the electric bed, that Shaun can sit up and erm... be more in control..."*

This couple's strategy was through using technology in the form of the Intimate Rider. The Intimate Rider is a piece of equipment which enables men with paralysis to enhance their mobility during intercourse. It is advertised as equipment 'designed for people who REFUSE to let physical challenges get in the way' (Intimaterider.com, 2011). Its advertisements feature happy and attractive couples (including male models with 'hypermasculine' physiques). Thus, the marketing is aimed at disabled men who wish to *reclaim* the physicality synonymous with a masculine sex role. This usage and application of technology serves to reaffirm the blurred boundaries of the sexual body. For example, the Intimate Rider as a sexual tool positions such technologies as extensions of the sexual body. Thus, the sexual body become hybridised, a mix of flesh and machine, thus constituting a form of sexual cyborg (Haraway 1991).

Through using this product the couple could negotiate their difficulties with the physicality of intercourse. No-one else in the sample knew of the Intimate Rider, nor knew that other sex toys specifically designed for disabled people existed, suggesting that many more could benefit from such knowledge. Importantly, Hannah made reference to the absence of the product from the sex and disability advice and information offered by SCI charity literature, which, she said, *"there was nothing [featured] about the chairs out there, products, straps, swings and things to do. I just*

thought it was very narrow-minded..." The invention of products like the Intimate Rider (which was designed by a male paraplegic) contributes to wider debates about disabled sexuality which question whether assimilation into normative sexual categories is the most empowering and accessible sexual project for disabled people (see Shakespeare 2000). Much of the literature for the product features a reclamation discourse based on 'natural' and 'normal' ways of 'doing' (importantly, only) heterosex, thus affirming normative sexuality rather than challenging it. Thus, such normalising products may disrupt and hamper sexual and bodily experimentation and the discovery of new pleasures, methods, and possibilities which may be available to the (newly) impaired body.

Penetration and Spontaneity

Wilkerson (2002) suggests that the cultural compulsion to have intercourse obscures more creative polymorphous forms of sexuality. As Cacchioni (2007: 304, emphasis added) states, within heteronormative sexuality 'kissing, touching, and oral sex are relegated or demoted to 'foreplay' and not 'real sex', they are the *other* to the ideal of coitus ending in orgasm'. Thus penetration has 'the privileged place as the essential heterosexual act' (Jackson 1999: 171). For male participants who *couldn't* maintain an erection and therefore have penetrative sex, it remained central to their masculine identity. Bob, a sensory and physically impaired male, understood his inability to have penetrative sex with his late partner as reason for her suicide:

> **Bob:** "*On Sunday, 14th April she lay on her bed nude, saying she felt sexually unfulfilled [...] On 24th April she told me she was going out for a packet of cigarettes just before 19.30. The nearest shop is at the end of the road and, as she was a 'Coronation Street' viewer, I expected her*

back within five minutes but, as she hadn't returned by 20.15 I became slightly anxious. A few minutes later she rang saying: "Hi darling, I'm just having a coffee in Hammersmith, I'll see you later." I was slightly relieved, feeling she may have needed some time to herself but, two hours later, I had a 'phone-call from a guy who'd found her handbag on the wall by a small slipway near [name] Bridge. Her body was discovered, a couple of miles down-river, eleven days later [...] I feel that if full-scale intercourse had been a regular part of the relationship and if I'd sexually fulfilled her on that Sunday afternoon things could have been radically different."

Although a particularly distressing account, it is clear that Bob understands his inability to penetrate and sexually fulfil his partner as justified reasoning for her death, illustrating the normalising power of phallocentric discourse. As Potts (2000: 87) suggests, 'the "sexed" male body corresponds to the erect penis – the "hard on" is the essence of male sexuality'. Without an erect penis, Bob's sexuality becomes non-existent and he has failed both himself and his partner. Thus phallocentrism serves only to castrate and emasculate disabled men who may not be able to meet its demands (Drench 1992; Shakespeare 1996; Murphy 1990). Such emphasis put on the *functional* body, then, results in, as Galvin (2006: 502) argues, impairment being conceptualised as that which 'removes people's ability to engage in 'normal' sexual practices and/or their capacity to incite 'normal' sexual desire in others'.

However, other participants were able to resist phallocentrism and *decentre* penetration from sexual relations. This offered space for new forms of sexuality to flourish. Thus, the providing of sex and pleasure were, in essence, removed from the

penis and displaced to other body parts (e.g. tongue, fingers) – a finding that has been echoed elsewhere (Ostrander 2009; Sakellariou and Sawada 2006). For example, Abram, a severely impaired 35 year old man who used a sex worker to lose his virginity, said that his tongue was central. Thus a (necessary) decentring of the penis was cause for some men to learn to 'specialise' and excel in the sexual practices they *could* 'achieve', such as foreplay, oral sex, and mutual masturbation. For example, Robert said that he tries "*to show passion in other [non-penetrative] ways*" and that he "*wants to please in any way I physically can*". Tom felt similarly and said that he "*has to be the best you can possibly be at what you can do"*. However, such pressure to excel at performing *alternative* practices – as seen in the first section – merely mirrors and replicates conventional notions of the male body as the primary source of pleasure and thus remains grounded hegemonic masculine identities (Guldin 2000). It also reinforces the essential *reciprocity* of heterosex – the necessity of a mutual exchange of pleasure in order for sex to be deemed successful. However, it was acknowledged that alternative practices this could be 'more' pleasurable and beneficial to female sex partners:

> **Grace:** "*His physical limitations meant that he used fingers and tongue to very best effect. Also, he took time, lots and lots of time. One hour was minimum, more often two or more. Foreplay was everything and he always, always made sure I came first – more than once."*

In this account, Grace shows how alternative ('Othered') sexual practices, combined with the more time her disabled partner needed, made sex more pleasurable for her (See Vahldieck 1999). Thus her partner's impairment instigated the creation of pleasures which went beyond the standard phallocentric experience. Rembis states

(2010: 54) that some disabled people 'see disability as a vehicle for learning about and exploring their own sexuality, as well as that of their lover or partner, which they claim makes them a more sensitive and responsive, or in some cases, creative and courageous lover'. Guldin (2000: 236) claims that this is an 'inversion of ability/disability' whereby,

> 'physically non-disabled men become sexually disabled by their lack of sexual skill and sexual introspection. This "sexual disabling" of bodies that are—according to cultural definitions—functional, challenges notions not only of the "sexual body" and "sexuality" but also of what it means to be "disabled."

As with penetration, normative expectations of spontaneity were recognised within participants' stories. Media portrayals of sex have created an 'unreachable sexuality' with 'good sex' being positioned as spontaneous and adventurous (as well as mutually satisfying). Dune and Shuttleworth (2009) call this the 'myth of spontaneity' and argue that it not only is unrealistic for all, but undoubtedly excludes people with impairment, and also others such as women presumed to have Female Sexual Dysfunction and people with HIV/AIDS. The consequence of not achieving spontaneous sex is that 'people attribute these 'sexual difficulties' to a personal inability to act as prescribed in terms of this internalized sexual script' (Dune and Shuttleworth 2009: 106). Participants consistently drew upon the myth of spontaneity throughout the telling of their sexual stories and many explained that their sex lives were somehow not as good because they couldn't have spontaneous sex with partners. As Robert suggested, "*If they [women] like spontaneity then I'm buggered*". Moreover, most participants were unable to find strategies to combat a

lack of spontaneity. Spontaneity was felt to be compromised by a range of factors related to impairment, for example, using a hoist to get into bed; the management of catheters; or bodily factors such fatigue, pain, and incontinence.

Participants felt the act of 'being spontaneous', (although many had never experienced it), was sexier, more passionate, and gratifying, emphasising the extent to which internalised knowledges of sex are learned through popular culture. My analysis suggests that feelings about spontaneity had different meanings for men and women and was gendered according to dominant constructions. For example, two women in the sample said they felt frustrated that their immobility meant they couldn't spontaneously 'prepare' for sex by taking part in the feminine practices of 'throwing on sexy underwear' and 'seducing' their male partners and many men in the sample talked about spontaneity as a symbol of masculinity, virility and dominance: *"sometimes I'd like to be able whisk my wife in my arms, spread her on the kitchen-table or on the floor, and make love. Be in total control."* Shaun and his non-disabled wife Hannah said that they had, originally, struggled considerably with feelings about spontaneity:

> **Shaun:** *"Obviously it's the spontaneity you lose, which we're having to learn at the moment... we're being taught by different people that, you 'know, just because sex isn't spontaneous it's not that it's any worse... In fact, they say the better sexual encounters are the planned ones, so that's something that we've both got quite stereotypical views about how sex should be from watching pornographic films, not that we've done it recently, but when you grow up and watch that kind of thing, it gives you a very fake view of what sex is actually about..."*

The learning Shaun refers to in this quote occurred within a sex and disability workshop run by the organisation *Outsiders*, the only sex and disability organisation in the UK. *Outsiders* is an organisation which, despite being publicly celebrated within disability movements and disability sex right discourses, has attracted scholarly criticism, namely because 'the concept of a club especially for disabled people feeds traditional ideas about segregated provision, even in relation to socialising and sex' (Shakespeare at al 1996: 127). Based upon both the negative experiences of Outsiders of some other participants, and my own readings of its literature on sex and relationships, I propose that *Outsiders* is an organisation which affirms heteronormative essentialist perspectives of sexuality and reinforces individualist discourses of sexuality. However, Hannah and Shaun found the *Outsiders* workshop they attended very useful because it offered a chance to hear the sexual experiences of fellow delegates which made them realise that others are in similar situations.

For those participants who acquired disability in adulthood, and who had experienced spontaneous sex prior to impairment, the transition to post-injury positive sexual adjustment (Parker and Yau 2011) was difficult. Lucille's acquired SCI wholly transformed her sexual self:

> **Lucille:** *"Sometimes I think about stuff from the past and it really makes my heart skip a beat and I wish I could do those things all again, be spontaneous... Lack of spontaneity – having intercourse [has] become like a military operation – no coming in the door after work and getting amorous on the kitchen table! No… sliding board, un-creased sheet, catheter tube out of the way, a roll… hardly the stuff of a great sex life!*

And of course the harking back to what was how it was and how it wasn't ever going to be that way again. It changed everything, the enjoyment of sex, confidence, the ability to be happy."

Lucille's experiences echo existing research findings which have documented the catastrophic effects of sudden disability upon sexuality (Parker and Yau 2011; Tepper 1999, 2000). Spontaneous sexuality, for Lucille, has been replaced with sex which she likens to a "*military operation*"; she emphasises this by listing the equipment and processes which intercourse now requires. Lucille, like most other participants, problematically relates ideas of spontaneity to sexual freedom and liberation, and thus her inability to perform spontaneously is perceived as a failure which "*changed everything*". However, spontaneous sexuality, affirmed by the 'Cosmo conspiracy' (Shakespeare 2000), remains an ever-present dominant sexual narrative despite the fact that most of us seldom have access to spontaneous sexuality (particularly the "*kitchen table sex*" Lucille cites above) for a wide range of reasons. However, participants' attribution of an inability to perform spontaneously to impairment is confirmed and maintained through wider discursive constructions of the impaired body as incapable and asexual, and simultaneously through dominant narratives of sexuality.

Conclusion

To conclude, the impaired body – as that which can deviate from conventional forms and methods of sexual pleasure – challenges the very essence of heteronormative sexual pleasure and disturbs and shifts sexual embodied norms (Ostrander 2009). Most participants showed sexual agency in some form. Where the impaired body posed a challenge to mapped sexual pleasures (e.g. arousal, climax,

orgasm) through conventional means (e.g. penetration, intercourse), participants developed *strategies* for the acquisition of pleasure which expanded conservative notions of heteronormative pleasure. Strategies included, for example, expanding views on 'sex'; decentring the orgasm; and partaking in sexual exploration and experimentation which facilitated discovery of non-normative pleasures. Such experiences reveal the possibilities of pleasure that the materiality of impairment can open up. Thus the impaired body *can* successfully expand heterosex. However, these alternative pleasures were often considered by participants as inadequate, 'not the same', and 'unfinished', and thus unnatural and abnormal within the rubric of sexual normativity. Thus, to participants, the ability to recognise their bodies and impairments as rousing sites of sexual potentiality was undermined by prevailing heteronormative discourse and thus sexual agency wasn't automatically realised, acknowledged and celebrated.

Moreover, while disabled participants' feelings of bodily inadequacy (and 'body talk') were gendered, with men's concerns revolving around meeting a hegemonic masculine and sexual body and women's centred on meeting a feminine aesthetic, for both men and women it was found that *proximity* to the normative body was crucial, and that deviation could affect the ability to experience sexual pleasures. In terms of bodily function and the practicalities of impairment, my analysis suggests that despite the significant impact of the 'hard' realities of the impaired body (Wendell 1996) (such as tiredness, fatigue and pain), participants could adapt through devising strategies to deal with bodily difficulties once again illustrating sexual agency. Thus, although impairment can be problematic within the confines of conventional notions of what constitutes a 'sexual body', participants' management

and strategies ensured that their bodies could be sites of sexual pleasure and enjoyment.

Finally, the very physicality of heteronormative sexual activity was central to male and female participants who felt that their impaired bodies ‘restricted’ the normative gendered sexual role they wanted to perform. Likewise, spontaneous and penetrative sex remained the fixed norm from which other alternative sexual methods were judged. Findings show that for those disabled men who could resist and reject the oppressive requirements of hegemonic sexualities (such as phallocentrism and taking on a dominant gendered sex role), a more empowering sexual project was available whereby they excelled in non-penetrative practices, thus inverting ability/disability (Guldin 2000) to become defined as ‘better lovers’. Men’s exclusion from traditional gender identities (with regard to sexuality), could serve as an opportunity to play with, and negotiate, gender. Thus instead of the impaired body being *de*-gendered – a body stripped of gender – the impaired (male) body can be emancipated and unbound from the oppressive gender binaries and hegemonic masculinity maintained through heteronormativity and heterosexuality.

However, while disabled male participants *could* negotiate gendered sexual identities and performances, the scope for disabled women was limited. Women were found to seldom have the manoeuvrability and agency of men when defining – or at least narrating – their sexual selves. Instead, findings have shown that disabled women had little alternative sexuality to claim, and thus remained feeling ‘not enough’ for, and not adequately meeting the (assumed) needs of, male sexual partners. For example, while many women desired a more active role within their sex, this was rarely achieved. Women’s accounts of their sexual selves and

relationships suggest that this is as much because of the restrictive boundaries of normative female sexuality, (which is characterised by passivity and asexuality), as the embodied realities of impairment. Thus, (disabled) men's increased social and sexual power offered more scope – either through acceptance or rejection of hegemonic masculinity – for men to negotiate a more empowering alternative sexual role.

Chapter 7: Going Over to the 'Dark' Side: Experiences of Commercial and Non-commercial Facilitated Sex

Introduction

This chapter focuses on participants' experiences of commercial facilitated sex and to a lesser extent their experiences of non-commercial facilitated sex. Forms of facilitated sex can be sites of contention which encompass moral, social, practical, financial, legal and emotional issues (Mona 2003; Shuttleworth 2010; Earle 1999, 2001). Such debates take place both inside and outside of the academy and reach the very heart of emerging disabled peoples' sexual politics and their campaigns for sexual citizenship (Sanders 2008; Plummer 2003). Information about commercial and non-commercial facilitated sex is not only seriously under-represented within disability and sexuality research (Shuttleworth 2010; Sanders 2007), (possibly because of their 'deviant' disposition), but routinely risk contaminating disabled male sexualities with connotations of the realms of deviancy and ethical ambiguity, thus reinforcing ableist constructions of disabled sexualities as Other and inappropriate.

In this chapter I build on my critique of heteronormativity. I explore the experiences of participants who engaged in commercial and non-commercial forms of facilitated sex and those who did not, in order to capture the range of attitudes and experiences regarding these forms of sexuality. I initially discuss the way a discourse of 'rights to sex' has been used in disabled peoples' campaigns for sexual citizenship to legitimatise the practices of commercial and non-commercial facilitated sex. Following this, the chapter is divided into two sections. Focusing initially on commercial sex, I look at the motivations of disabled participants who purchase sex – all men – and locate them in dominant constructions of disability *and* masculinity. I

then explore the complex power relationships between disabled men and non-disabled female sex workers within commercial sex relationships. In the second section I examine participants' experiences of non-commercial facilitated sex, focusing predominantly on the integral role of the PA within commercial sex purchases and the highly contentious practice of assisted masturbation. I conclude that both commercial and non-commercial facilitated sex are practices problematically embedded within conventional gendered ideologies of power, heteronormativity, and masculinity. This not only serves to define, exclude and marginalise the sexual desires of disabled women, but reaffirm and maintain discourses of heteronormative sexuality which, as I have argued throughout this thesis, can oppress and exclude disabled people.

(Gendered) 'Rights' to Sexual Pleasure

International discourses of sexual rights increasingly recognise sexual pleasure 'as a human right' (Oriel 2005: 392; see also Petchesky 2000). For example, the World Health Organisation's (2002: 3) definition of sexual rights lists, among other sexual health-related rights, the right to 'pursue a satisfying, safe and pleasurable sexual life'. It is the lexicon of 'satisfying' and 'pleasurable' that makes the WHO's definition distinct from other rights documents. Such rights have been problematised by feminists on grounds of their gender-neutral language (Jeffreys 2008; Oriel 2005) and their failure to 'explain how the right to sexual pleasure, or any sexual right, may affect women and men differently' (Oriel 2005: 392). However, Kanguade (2010: 197) argues that 'the concept of sexual rights is a powerful tool to expose the relationship between human rights and the sexuality of persons with disabilities (sic)'.

In order to become ‘full sexual subjects’ (Kanguade 2010: 197) disabled people have begun campaigning for their sexual citizenship within a rights-based framework which, Sanders (2010: 151) argues, has offered activists ‘a means to speak out about sexual oppression’. A rights-based framework is argued to legitimise disabled peoples’ sexual and intimate desires by placing them firmly on the agendas of disability rights movements (see Tepper 2000), and doing so has ended the historical absence of sexual life from a disability rights agenda (see chapter two). This framing of sexuality follows on from disabled peoples’ campaigns for rights within public life; as Davies (2000: 188) protests, ‘we’ve fought for equality in terms of access to the built environment, to education and employment and now we want our rights to love, form relationships, and have sex with ourselves and with other people’.

Thus, notions of rights to pleasure are becoming increasingly normalised within disability activist spaces (e.g. Disability Now Let’s Talk About Sex!; Sexual Freedom Coalition 2008; The Outsiders’ Free Speech Campaign 2009; Sexual Health and Disability Alliance 2011) and this discourse of rights has been used to legitimatise the practices of commercial and non-commercial facilitated sex. Commercial sex facilitation takes place through purchasing sexual services from a sex worker or sex surrogate. A sex worker sells sexual services, and a sex surrogate is a worker who provides, according to Shapiro (2002: 4), ‘a therapeutic process which attempts to have the patient begin a dialogue with their own body in an attempt to, in a meaningful way, transcend simple gratification’ (see also Davies 2000; Shuttleworth 2010). Non-commercial sex facilitation, however, is usually carried out by a personal assistant or carer and can encompass a range of practices;

for example to assist social or sexual life, facilitate commercial sex work exchanges, or, as Earle (1999: 312) proposes, 'a person [PA] might be required to facilitate sexual intercourse between two or more individuals, to undress them for such a purpose, or to masturbate them when no other form of sexual relief is available'.

Purchasing Sex: Gender Dimensions

Disability publication *Disability Now*'s 'Time to talk sex' survey of 1115 disabled people conducted in 2005 revealed that 22% of disabled male respondents reported having paid for sexual services in comparison to just 1% of disabled women (Disability Now 2005). Similarly, just 16.2% of disabled women had *considered* paying for sex in comparison to 37.6% of disabled men. There are no comparative statistics for non-disabled men and women (Sanders 2005; see also Wellings et al 1994). Reflecting these findings, out of a total of sixteen of my male participants, seven had purchased sex from a sex worker (one had additionally purchased sexual surrogacy) and all ten female participants said they had never purchased sex, though one said she had considered it (see chapter four). The lack of women's experiences mirrors the widespread absence in both academic and non-academic fields of women as sex purchasers, although there are some exceptions (see Barnes 2009; Browne and Russell 2005). However, while the voices and experiences of female participants may be in short supply throughout this chapter due to a lack of data (see below), I argue that this lack of data *is* data. Thus disabled female sexuality – notably its absence from commercial and non-commercial sex – reinforces the highly gendered nature of such practices and, as I go on to argue, that such practices *reproduce* a heteronormative sexuality which is predicated on a mode of sexuality that requires

female passivity, meaning disabled women are unable to act in the same ways as disabled men.

Male and female participants offered various responses to questions regarding commercial and non-commercial facilitated sex, and commonly expressed disgust, interest, or indifference. While men who hadn't engaged in such practices offered full explanations for their reluctance (discussed later), many female participants' responded with laughter and shock. This is because women as purchasers of sex conflicts with constructions of female sexuality and thus it is a route to sexual expression seldom available to women (disabled or otherwise). Past this initial reaction, very little was said by women about purchasing sex and sex work, which is contradictory to existing research carried out by Browne and Russell (2005: 392) where disabled women expressed their views, for example, about the 'lack of opportunities for them to engage in commercial sex', 'the idea of a [paid for] fuck buddy' and their feelings about cost implications. Female participants in my research were, however, more vocal in their disapproval of particular forms of non-commercial sex facilitation (e.g. assisted masturbation by a PA) than of commercial sex, which is discussed in following section.

All male participants who had purchased sex said they were not in a relationship at the time. For younger participants, purchasing sex offered their first sexual encounter. These participants sought to purchase heterosexual and heteronormative sexual services from female sex workers; no experiences of 'alternative sexual practices' (Reynolds 2007: 40) such as kink, BDSM (bondage, dominance, sadism, and masochism) or fetish practices were mentioned. The potential illegalities of their actions, safe sex or sexual health (despite often taking

part in ‘risky’ activities) were seldom raised. However, the absence of concern about illegality may have been because most sex purchases were made within indoor sex markets such as brothels, working premises, and sex workers visiting participants at home (Sanders 2005); thus there was less of a requirement to ‘solicit’ (as the illegal element of purchasing sex in UK law). It is also because indoor sex workers are much less considered to be ‘contaminated spreaders of disease’ which is an identity more often ascribed to street workers in outdoor markets (Sanders 2008).

Decision-making: Beyond ‘Need’

Sex work is a hotbed of feminist debate (see LeMoncheck 1997; O’Connell-Davidson 2002). Radical feminists predominantly use terms such as ‘prostituted women’ (Jeffreys 2008; Raymond 2004) and ‘prostitute user’ (Raymond 2004), and argue for the abolition of prostitution. This is on the grounds that male purchasing of women’s bodies is a form of sexual exploitation supported by and reproducing the ‘male sex right’ (Pateman 1988): ‘the privileged expectation in male dominant societies that men should have sexual access to the bodies of women as of right’ (Jeffreys 2008: 328). Moreover, ‘prostitution’ is positioned as deeply harmful for women sex workers because it requires ‘self-estrangement’ (Chapkis 1997), commodifies the female subjectivity and body, can impact upon their personal sexual subjectivity and relationships (see Hoigard and Finstad 1992) and thus equates to a form of sexual violence (Jeffreys 2008). However, other feminists, who apply terms such as ‘sexual labour’ (Boris et al 2010), ‘sex workers’ and ‘clients’ (Sanders 2007, 2008, 2010), ‘sex surrogates’ (Noonan 1984), and ‘johns’ (Holt and Blevins 2007), conceptualise prostitution as inevitable within capitalist society where the sexual body has become another commodity. As such, they argue that ‘prostitution’ should

be recognised as a legitimate form of labour and commercial service work (see Boris et al 2010), which requires survival strategies similar to conventional service work (Weinberg et al 1999), and where regulation of the industry would offer sex workers legal, political and civil rights (see Chapkis 1997; Jennes 1990). While space precludes me from highlighting the broad spectrum of debate between these two polar positions here, they are fleshed out within this chapter.

Existing research has shown that non-disabled males who purchase sex often have multiple reasons for doing so which extend beyond 'needing' sexual release or gratification (Sanders 2007; Campbell 1998; McCabe et al 2000). For example, in her research with (non-disabled) male customers, Campbell's (1998) male participants said that their motivations to buy sex were based on 'excitement; sexual services not provided by current partner; sexual variety; convenience; lack of emotional ties; loneliness; and an inability to form sexual relationships' (in Sanders 2007: 444). Additionally, motivations such as unattractiveness, poor sexual development (Atchison et al 1998), and thrill (Monto 2000) have been cited. However, other research reports that men's 'commercial sexual relationships can mirror the traditional romance, courtship rituals, modes and meanings of communication, sexual familiarity, mutual satisfaction and emotional intimacies found in 'ordinary' relationships' (Sanders 2008: 400).

However, disabled men's purchasing of sex is often constructed within disability rights campaigns and certain areas of feminist sex work literature far more upon an unmet biologically-based 'need' for sexual gratification (Hollway 1994). For example, disability rights campaigns for sexual citizenship (particularly those advocating the availability of commercial sex) position disabled men as deeply

sexually frustrated, wronged (in that their unnatural manly needs are left unmet), and thus as sexual victims (Shakespeare et al 1996). The TLC Trust, a British organisation aimed at 'helping professional sex workers and other service providers cater to the needs of the sexually dispossessed (sic)' (TLCtrust.org.uk, 2011), advocates commercial sex for disabled people (men) on the basis that sex workers '*rescue* disabled people from personal *anguish*, sexual *purgatory*, and touch *deprivation'* (TLCtrust.org.uk, 2011, my emphasis). Perplexingly, this legitimation of meeting male needs is replicated in the literature of 'sex radical feminists' (O'Connell-Davidson 2002: 88) – who form the 'opposition' to radical feminism – and define prostitution as a socially valuable form of work, and especially more acceptable for 'disabled people, folks with chronic or terminal illnesses, the elderly, and the sexually dysfunctional' (Califia 1994: 245). As O'Connell-Davidson (2002: 88) suggests, 'the implication is that sex work should be respected and socially honoured because it expresses a form of care or creativity'. Furthermore, experiencing sexual pleasure for disabled men is far more entwined within notions of 'quality of life' – though this has been argued for non-disabled men too (see Sanders 2008) – with campaigns positioning access to 'sexual relief' as essential to disabled men's psychological, emotional, sexual and bodily well-being (see Browne and Russell 2005). However, in contrast to this, for the most part, my participants offered a wide variety of motivations behind their decision to purchase sex and used a much wider lexicon of explanation which extended well beyond essentialist notions of biological 'need' (Holland et al 1998) and, simultaneously, was in part tied into the social, cultural and material disenfranchisement of disablement. However, these *could* include explicit and implicit references to men's 'need' for sex:

Kadeem: "*I needed sex 'cos I do get really horny*"

Terry: *"I just felt like I needed sex, I don't want to say it was like a fix because it wasn't like I was craving it, but it was just the fact that – for me it's a solution – it's a solution to wanting to have sex a lot."*

Being "*horny*" and "*needing sex*" are enactments of a normative masculinity to which disabled men are often denied (Shakespeare 1997). Terry and Kadeem offer typically gendered performances through which they attribute their sex purchases to (male) *need*, thus being entrenched within a male biological sex drive discourse where ejaculation is a required bodily 'release' (Hollway 1994; see also O'Connell Davidson 2002).

However, most men offered more extensive reasoning as to why they made the choice to purchase sex. This could have been because that these male participants felt they had to offer 'valid' and substantive reasons to 'justify' a socially unacceptable practice. It also may have been exacerbated by the fact they were being interviewed by a female (presumed feminist) researcher. A couple of participants referred to "*ardent feminists*" through their stories about sex purchasing (usually in the context of chastising their actions), and some participants were often overly-apologetic and cautious about how they were being perceived while story-telling: "*I hope you don't think I'm a pervert..."* However, men's extensive explanations also suggest that although 'need' is a powerful discourse, it is not enough to justify the practice (see Sanders 2008). For example, for Abram, aged 35, who had a severe impairment requiring 24 hour care, and who purchased sex from a sex worker, and for Graham, aged 52, who purchased sexual surrogacy, doing so was a way to gain 'necessary' sexual experience and skills:

Abram: *"And then she sort of started kissing me … I'd never even been kissed before [long pause] …I think the first thought was how wet her lips were. It was new and I tried to get my lip action going a bit as well. I was able to just experiment, really. And just learn a little bit more what I'm capable of – there was one point where she was sort of sat on my face and just let me lick her and taste her. And I'd always wondered about that – I can't stick my tongue out very far so I always sort of wondered 'what could I do with my tongue in that respect?' Well, now I know. And it was probably better than I thought I would be capable of."*

Graham: *"It was the first time I realised a woman's body was warm, with no clothes on, naked, she was warm and that was a shock to me."*

Erotophobic social environments, where 'disabled adults have been infantilised, sterilised, prohibited from engaging in sexuality and marriage and excluded from mainstream social and leisure activities' (Bonnie 2004: 125) can mean disabled people may lack opportunities for sexual experiences (see chapter four). This, combined with the compulsory and persistent sexuality ascribed to male bodies as part of hegemonic masculinity and heteronormativity, can make purchasing sex and sexual surrogacy a fruitful means for disabled men to gain such experiences. Graham's account highlights the deprivation of sensuous feeling that can be part of the disabled experience. His experience also illustrates how sexual surrogacy is understood as 'well suited to treating the lack in psychoemotional development and sexual confidence that some disabled people exhibit as a result of the sexual barriers they face and their sociosexual isolation in adolescence and young adulthood' (Shuttleworth 2010: 6). Thus, it can 'function as a real and meaningful form of erotic

communication and self-realization' (Shapiro 2002: 72). However, while sex surrogacy is supposed to offer more intimate and sensual contact than with a sex worker (Noonan 1984), Shakespeare et al (1996: 132) express caution that it serves to locate disabled sexualities within a medicalised and therapeutic context, thus reinforcing a medical model of disability. Additionally, while paying to learn sexual skills with a sex worker is conceived as an answer towards solving the 'problem' of disabled men like Abram feeling 'inadequate' or inexperienced as lovers (in terms of heteronormative sexuality at least), as is recognised in the literature (Shuttleworth 2002; Aloni & Katz, 2003), it is likely that the commercial context of a sex purchase detracts from 'genuine' learning. Jeffreys (2008: 334) argues that disabled men are likely to learn a 'depersonalised, objectifying form of sexuality' rather than one which is mutual, shared, and reciprocated. Moreover, it reinforces dominant notions of male sexuality being about technique, and that male performance is based upon him 'doing' something to her.

Abram also said his decision to purchase sex was centred upon concern for the well-being of his "sexual body", and that purchasing sex was a way to invigorate his sexually 'defunct' body:

> **Abram:** *"Up until [purchasing sex], for a couple of months I'd barely felt any stirring at all down there. I was beginning to think that, physically, my body's given up. That's one of the reasons why I was really desperate to do this... to reassure myself that my body hadn't given up. When I did used to ejaculate in my sleep and it'd be a, you know, an embarrassing, messy business; but then it kind of stopped happening. And that can be even worse. That I'm feeling nothing; I'm just feeling*

complete emptiness. I think this whole experience kind of woke that up in me again, in that there were days afterwards where I was feeling excited. And I felt like there were things happening down there, and it was just giving me a buzz."

Thus, for Abram, the act of *having* sexual relations sexualised both his sexual-self and his physical sexual body. His lack of previous sexual excitement and ejaculation ("*stirring*"), as a man, left him feeling "*complete emptiness"* and experiencing this through purchasing sex reaffirmed his male sexual capacity and potency. Notably, Abram was the only participant in the sample to be interviewed twice. During his first interview he talked extensively about how he had 'trained' his body and mind to "*shut down*" the desire for sex and a relationship. However, a few weeks after this interview he got in touch again to say that talking about his experiences had been a catalyst towards making changes in his life (discussed later), and that he'd lost his virginity to a sex worker and wanted to be re-interviewed about his experiences.

Equating *feeling* and *being* sexy to sexual *action* with a woman was a common assertion by male participants, tying in with dominant hegemonic notions of 'doing masculinity'. For example, Graham said *"there needs to some sort of proof [to feel sexy], like having girlfriends, having sex, all that, that's the proof that you are... [sexy]"*. Tony said that as a virgin he'd never been in a situation to "*feel sexy*" and Mark said that purchasing sex made him "*feel very sexy*". Needing affirmation of desirability from a partner (paid or otherwise) to 'feel sexy' may also be rooted in disabled peoples' distance from normative bodily aesthetics. However, for Harjit, purchasing sex was not only to feel sexy, but also about having something to contribute when friends discussed sex:

Harjit: *"Erm, I had been looking around for an escort for a while and just thought... well, a lot of my friends go out and they talk about it [sex] and you see it happening and you hear about it [sex] and it was just like I don't see why I can't... but to find a place [to have sex], to find a time... again, I'm always with parents at home so there's no privacy whatsoever."*

Thus, being able to contribute a sexual experience to friends' discussions made Harjit feel more included in the masculine sexual cultures of his friends. Harjit was one of two participants who were both severely impaired and came from what they identified as restrictive ethnic and cultural backgrounds. Harjit, 23, lived with his African immigrant parents, while Abram came from a British Asian background. Their stories were similar in that they both felt infantilised by over-bearing families, which can be part of the disability experience (Morris 1993; Shakespeare et al. 1996; Brown 1994), who allowed them little financial control of their own money. Thus, their purchasing of sex was embedded within a wider emancipatory narrative and both men told of elaborate escapades which were meticulously planned and enthusiastically retold through the interview:

Harjit: *"There's lots of thing you have to consider because, erm, you've got to try and see when you can get away from home and all my money matters, all my bank statements everything like that goes to my parents and they open it. They scrutinise it [Harjit's spending***]***. I had to draw cash out [to pay for sex]. Erm, what would I tell them? Where am I going? 'Cos if I'm not home they'll probably go out for a walk, so what I am going to do if they find me where I'm not supposed to be? So if I'm*

walking around in town, what am I going to say? [...] It just so happened that they had to go to [city] last week and my grandmother was here so, again, getting in and out of the building is a lot easier when there is someone to open the door for you. I told her, "look, I'm going to uni and I have to go for a meeting" but erm... and I told my mum "I'm going to be out for a couple of hours, probably, go to my meeting and then on to the library". [Whispers] which I didn't... but I had to think of something, Well... I had to change my whole banking system so that I don't get any statements and it's all done online so that my parents won't see that I withdrew that much cash out... Hopefully now I won't get asked "Why did you withdraw...?"

Abram: *"Yeah, I normally need to get cash. And every now and again my dad will look in my wallet and say "you've got £20 – do you need some more money? How much do you want?" And I was just, I didn't want to keep, like, sneaking bits of money out, and then saying "can I have more money?" It kind of seemed a little bit duplicitous, but I had some cash that my dad had left in a drawer for emergencies. It was about a £180 or something, but I didn't just want to use all that up because I never knew when my dad would go looking there again. I took bits out of there and I got most of – well, I got about half of the money I needed from that, thinking that 'he doesn't look in there that often – I'll just try and sneak a bit more money back in – and top it back up to what it was before'. And I started to try and pay by card for things when I went out shopping that I would normally pay for by cash [via Cash Back] so if my*

dad noticed that I was running low on money he wouldn't start to wonder why it was; he'd think 'oh yeah, he went shopping'. So eventually I got there... I'd arranged it for Sunday night. I wanted it to be private from my parents and I managed to make it happen and managed to organise it. I managed to ensure my parents had no idea. Um … and anyone that does know are only people that I've chosen to let know."

These stories, firstly, are indicative of the lack of autonomy many disabled people experience throughout their lives. Secondly, such stories are significantly different to the stories of other male participants from other backgrounds but of similar ages. From the excitable way such stories were told it appeared that a lot of the "*buzz*" both men said they got from their respective sex purchases was as much from exercising agency, control and independence as it was about experiencing sex or sexual gratification.

However, for other male participants, sex was purchased because it was an *easier* process than either a willingness to invest money and time in dating before sex or because they said they had little access to sites where they could meet prospective parties:

Terry: *"I knew that I wasn't going to be able just to walk into a – you know – so it just seemed like an easy route before university. I wanted to feel that experience because it had been a while and I can't go into a nightclub and easily pull, although I have in certain circumstances but I wouldn't – I can't do it easily. So this is really just like a short-term fix, really."*

Kadeem: *"I didn't wanna pay, I wish I could go out and meet someone but it's not that easy".*

While Terry's account reflects findings in research on non-disabled men's motivations, for example, that paying for sex can mean evading 'the added burden of the 'courting' rituals that are expected in heterosexual interactions' (Sanders 2008: 43), Kadeem's account highlights that the ways in which disabled peoples' exclusion from social and sexual spaces can compound this issue. These include the general inaccessibility (as well as cost) of adult meeting spaces such as pubs and clubs (Shakespeare 2000; Earle 1999), and attitudinal barriers and discrimination (particularly verbal abuse) that many of my participants experienced while visiting such places. The attitudes of prospective (sexual) partners can also pose a major problem; as Shakespeare et al (1996) suggest, the difficulty of sex for many disabled people is not how to do it, but who to do it with (see also Rintala et al 1997). While non-disabled men may equally experience this, the social undesirability of the disabled identity generally within ableist cultures, the possible non-normative embodiment, and the low self-esteem endemic to the disabled experience intensify this issue.

Other men said that they were paying for, as Tom stated, "*a different type of sex*":

Terry: "*When you pay for sex you've got a sense of – you get a really different feeling from what you would get from being in a consensual relationship. You feel more – I don't want to say powerful, because you're not. You feel – you feel very – everything's directed towards you, and everything in the sex is to your standards. So it's more –when I'm in a relationship with someone probably around ninety percent of what I'm*

thinking is if they're going to enjoy it; is it okay for them?' Whereas with someone you're paying for you don't have that kind of stress of demand – it's quite easy for you and everything is directed towards you. So you can just relax, instead of trying to share the experience with someone else."

Abram: *"I was able to experiment without guilt, without the tension of worrying about how the other person feels; in particular how they feel about how limited I am in what pleasure I can give. By paying I didn't have to worry. In fact I think at one point I did, and she just sort of like smiled and told me, like, 'forget about it - this is for you'."*

These accounts show that one of the benefits of purchasing sex from a sex worker is being able to relinquish active responsibility for producing a woman's pleasure. Non-disabled men have been found to also pay for sex for this reason (see Sanders 2008; Campbell 1998), thus contradicting Califia's (1994) proposition of disabled men's sex purchases as having a higher 'social value' than those of non-disabled men. However, abandonment of the role of the male pleasure provider may be exacerbated for disabled men who, because of the possible restrictions that impairment, non-normative socio-sexual development, and constructions of normative sex place upon sexual practices, may feel more inadequate in the role of a pleasure provider (particularly in normative ways) than non-disabled men (see chapter six).

Thus, while my male participants offered a variety of motivations for purchasing sex, many of which were embedded within the masculine constructs of sexuality and the disabled identity, it is important to consider those who had not paid for sex. Impairment does not make paying for sex inevitable; as Sanders (2007: 452) argues,

> ‘Men with impairments do not just visit sex workers because they have an impairment. Like non-disabled men, they visit sex workers because they have unfulfilled sexual desires for a range of reasons.’

Of my sample, nine out of sixteen male participants and all ten of the female participants had *never* purchased sex. Male participants offered a variety of reasons why they *hadn’t* purchased sex:

> **Bob:** *“I've yet to have my first encounter. There was an occasion, about five years ago, when I was walking at King's Cross station, when a slightly bedraggled-looking girl approached me saying how much fun we could have together. I asked her how much she charged; she asked me how much I had but I'd decided by that point that I didn't want to proceed. She seemed half asleep; I assumed she was probably a drug-addict. I felt sorry for her, as she seemed so potentially vulnerable, and saddened that anyone should opt for that sort of lifestyle. I felt that I'd have to be pretty desperate to agree to anything in these circumstances.”*
>
> **Robert:** *“Now, I still maintain I wouldn’t, but I have considered it more. I know only disabled people who have. That makes me feel mixed. My yardstick is an average life. If generally people don’t, I won’t. But then, I could be enticed... Overall it’s still a no as I would feel failed, dirty and probably worse afterward as it'd have no meaning.”*
>
> **Pete:** “*To be honest, I have always been frightened of catching some disease. It has never really entered my head to pay for sex. I wouldn't*

know where to buy sex, Kirsty, even if I wanted it. I'd probably get turned away anyway!"

Phillip: *"I haven't and I wouldn't seek to. Again, however, whether you were to ask me that question again in 20 years time... The biggest issue for me in paying for sex is that erm, about exploitation. I worry about the girls being exploited... But that isn't to mean, if they weren't exploited, I wouldn't tomorrow go and pay for it."*

Thus, reasons such as concern for sex workers; moral objections; fear; not knowing how or where to buy sex and not 'needing' to (because they had access to sex in their intimate relationships) were offered. Additionally, some men feared that paying for sex would confirm them as an object of disgust or pity; as O'brien (1990: 13) states, 'hiring a prostitute implies that I cannot be loved, body and soul, just body or soul'. However, the accounts above are indicative of the general ambiguity of male responses to sex purchasing. For example, Bob, Robert, and Phillip's accounts all admit the potential for purchasing sex, although it's a practice they have not "*yet*" engaged (Bob); one to which they "*could be enticed" (Robert),* especially if exploitation weren't involved. Therefore, for most male participants who had not engaged in commercial sex work it was implied that doing so wasn't out of their reach as disabled men. This potentiality, in comparison to non-purchasing women's silences, illustrates the highly gendered nature of sex work, but also that purchasing sex is a very heteronormative form of opportunity, and one that is predicated on women, because of constructions of normative female sexuality, not being able to act in the same way.

Making the Purchase: Value, Fulfilment and Power

Due to their exclusion from the labour market many disabled men pay for commercial sex through statutory government benefits (Sanders 2007), and this is how many of my participants paid for sex purchases. Many said they had to search for the cheapest price, a rational justification which fits with disabled peoples' general lower socio-economic position (Shakespeare 2001). Thus, for most, sex purchases were restricted by income making price a crucial factor:

> **Terry:** *"I think the rates are extortionate for what you're having [...] Erm, but you know – it's a market. And anyone can price themselves however they want in that market."*
>
> **Abram:** *"It was £150. Um ... yeah, it seemed a very, very unusual thing parting with that much cash. Erm… because the weekend before, I'd gone to a gig and that cost me, like, twenty-five quid. And it went on for three hours. And I was thinking, this is six times as much and it's going to last one hour."*
>
> **Mark:** *"Yes, I remember exactly how much I paid, it was the cheapest I could find, £100. The rates haven't seem to have gone up in 15 years. Which is good for the clients, but not for the ladies."*

Terry's account denies the value of female sex workers providing sex ("*extortionate*"), and he acknowledges that, as an unregulated market (thus not linked to inflation), sex workers can (in theory) charge whatever they like. This was emphasised by one participant asserting that his sex worker sometimes had *"special offers on*". However, Mark's recognition of the stagnancy of pricing corresponds

with academic accounts which demonstrate that sex workers have few rights or protection in the sex trade. What is more, these men's accounts suggest that conceptualisations of what they were paying for were the use of a worker's body, rather than her personhood and subjectivity. O'Connell-Davidson (2002: 86) states that within the prostitution contract the purchaser doesn't *buy* the person, instead he buys the temporary 'fully alienable labour power'. Feminists debate whether this is a violation of human rights and an exploitative loss of self for the worker and thus emblematic of male domination (see Jeffreys 2008; Raymond 2004), or a productive instrument which the worker uses within the commercial transaction: thus she temporarily suspends her 'self' rather than loses it completely (see Chapkiss 1997). Importantly, the above protestations about cost show that men based their conceptualisations of price for sex on the service as an *unembodied* exchange, and that, women *providing* sex costs them nothing, they merely provide a body.

For most men, the value of the exchange was determined through the performance of the sex worker and most were able to distinguish what constitutes a 'good' and 'bad' sex worker. For example, a 'good' sex worker was 'chaste' in that many men preferred sex workers who were new to sex work or not very experienced, or who were selective about customers. At the same time she must be cheap, attractive, professional, punctual, accommodating to male confidence and access needs, knowledgeable about impairment and disability, available, honest, warm and genuine (not too mechanical in her work), good at chat/pleasantries, not too concerned about time, who doesn't rob, steal or manipulate, and who is convincing in that she wants to be having sex with the client. Meanwhile a bad sex worker (who did not offer 'value for money') was rough, mechanical, rushed or speedy (therefore

too aware of time), under the influence of drugs or alcohol, unaccommodating, had too many 'rules' (e.g. no kissing), was deceitful, rejecting, unattractive, fat, old, and according to one man, 'not black'. Thus men constructed sex workers through their stories which bolstered their power as male purchasers:

> **Abram:** *"Erm, I was looking [online] at two [sex workers]. I first started looking at [name], but it seemed like she'd been round the block a few times, she was sort of quite well-known, I think. She seemed like she was very comfortable with just about every ailment [disability]. And – although she seemed to be very popular– and, sort of very, um, very well-known, she didn't apply partly because of her experience... And also the fact I didn't really see myself with a black woman, if I'm honest – it's just not my – not my bag [Laughs]..."*

Abram's assertion that the sex worker he did not choose had "*been round the block a few times*" and was "*very comfortable with just about every ailment"* is problematic in that what many men also wanted was the illusion that sex work was not her occupation and the professionalism and knowledge of impairment/disability, both of which only come with a worker with experience. Abram went on to say that the sex worker he did choose was attractive, the right age, and was, as he puts it, "*spiritual*", showing the "*right attitude*" and thus was of good character. His attraction to a sex worker who showed the "*right attitude*" of being inclusive and accommodating demonstrates men's fears that sex workers can knowingly capitalise upon their social exclusion and marginalisation. For example, showing an awareness of the desexualisation of disabled people and thus seeking to understand the social context of why disabled men may purchase sex can be profitable. Abram's declaration that a

black woman is not his ‘bag’ highlights his racialisation of sex work; ethnicity was also a factor for Harjit:

> **Harjit:** *“It was a choice of two really, a polish or an English... who were working at the flat. There were more at the other building, but... I thought English was easier to speak to and try and explain to her what needs to be done.”*

Harjit’s account accepts the racialised hierarchy of sex workers, relating it to communication as part of the purchase (O’Connell-Davidson 2003). He also recreates and reproduces the routine objectification and dehumanisation of sex workers: “*a Polish or an English”.* Some participants deliberately broke a sex worker’s rules, which refuses the worker’s right to outline the contact she’s willing to make, and again asserts male purchase power. For example, rules such as “*no kissing*” and, as Mark asserted, the “*come once rule*”, whereby it is ‘polite etiquette’ for the client ejaculate once during the purchase were routinely broken. Mark told how he deliberately broke the ‘come once rule’ whereby he would ejaculate early on in the purchase, and then break the rule by ejaculating again just before the end. Situations like this reinforce the actual power disabled men experience in these interactions. Rules can be set by the worker, but a worker has little protection or means through which to assert herself, short of not seeing a particular client again; and, if she works for an agency, this may not even be her choice.

Furthermore, male participants said it was important that the sex worker appeared to care about her work, not dissimilar to the requirements expressed by non-disabled men in existing research (see Sanders 2008). For example, Holt and Blevins (2007: 346-347) found that for male purchasers ‘the quality of the sexual

experience depended heavily on the attitude and demeanour of the prostitute', with sex workers 'who vigorously performed during intercourse or appeared to enjoy the sexual act' preferred. 'Good value' purchases were not just (sexually) fulfilling and enjoyable for my participants, but also believable, convincing, and authentic:

> **Abram:** *"She [sex worker] wanted to do it well and kind of make a difference to someone. Not just 'give me the cash – wham-bam out of here'... I never felt like she was just doing it for the money"*
>
> **Mark:** *"It occurred to me I guess some people just enjoy it, it's not just the sex part, it's actually making someone happy, spending time with people, they like that other aspect of it. [Enjoy it?] I think so yes. [Long pause]"*

In contrast, some were clear that sex purchases were 'fake', as Graham stated: "*I want it to be real and... It's a fake, it's a fake, it is pretence, it's not real, but that's the only way I can get women".* Other men said that a 'bad' sex worker rushed, or was too formulaic in her work:

> **Kadeem:** *"'cos you're payin' them, it was rushed, and was fake for them... they go through [the] process, bit at a time, like kissin, then they let you suck their tits, and they get you hard and get on top, [then] they finish off with blow job. But they did each bit for few minutes, like tryin' to fit it all in and finishin' it off... was crap. I enjoyed waitin' for them and when they first start it's nice but then you start realisin' they rushin' and not that into it [and] then you're just goin' through process."*

Kadeem believes that his sex worker did not offer enough variety or spontaneity, making him feel like it was routine for her and thus she provided a less genuine performance than he would have liked. Kadeem preferred the idea of sex surrogacy (but couldn't afford it) because it offered the "*girlfriend experience*", identified as the 'ideal' relationship with a sex worker (see Bernstein 2007; Sharpe and Earle 2003), in which 'the woman is enthusiastic about the sex act and makes the john feel special, as though they are in a non-commercial consensual relationship' (Holt and Blevins 2007: 336). Graham made similar distinctions between sex surrogates and sex workers, saying that sex surrogates made him feel "*comfortable*", "*relaxed*", and that they "*took the responsibility off*" while sex workers made him feel "*uncomfortable*", "*horrible*" and like there was "*no option – it was that or nothing*".

The roles of sex worker and sex surrogate, despite having different intentions and aims, are often conflated and misunderstood, with sex surrogates sometimes labelled as 'elitist prostitutes' (Roberts 1981). This originates from the fact that both are paid-for, commercial services and both involve sexual bodily contact (Shapiro 2002; see also Noonan 1984). Graham also said he got into significant debt paying for sex surrogacy, paying £400 per weekend for a 'one level' course with The School of ICASA, a UK sexual healing centre for surrogate partner therapy (www.icasa.co.uk 2011). Graham said he completed all 15 'levels' in quick succession (approx £6000) but that it was not as helpful as he'd hoped: *"I learnt a lot about love and intimacy but I learnt nothing about sexuality"*. Graham's words not only show how sexual '[surrogacy] can serve to reinforce feelings of inadequacy and difference' (Shakespeare et al 1996: 133), but that men's expenditure did not always match their assessment of the value of a purchase. Thus, for many participants 'good

value' was strongly related to sex and intimacy which felt *real*, was embodied, and thus *not* a mere economic exchange. Men weren't solely paying for the unemotional and mechanical sex as defined through talk about "*extortionate*" pricing above, indicating a discrepancy between price and value. As Holzman and Pines (1982: 112) argue, while male purchasers pay for sex, they do 'not want to deal with someone whose demeanour constantly reminded them of that fact'.

Very much in contrast to a 'good' and 'professional' worker, a 'bad' sex worker was heavily chastised in men's stories, as has also been found in the sex work stories of non-disabled men (Sanders 2008; Holt and Blevins 2007; Holzman and Pines 1982). The men made derogatory comments about a sex worker's appearance (see Holt and Blevins 2007); for example, a 'bad' sex worker was unattractive, old, or fat. Mark said, *"What came around was a woman in her mid-fifties, not attractive at all, a bit fat. [Laughs] If I don't find her attractive, I can't come [ejaculate]."*

A 'bad' sex worker also manipulated time. Some men said they had been 'short-changed' and thus not received value for money. For example, Harjit said he paid £140 for *"45 minutes of chat and 15 minutes of sex"*, while Kadeem said *"you pay between £120-150 for hour but you never get the hour, it's more like 20 minutes."* Manipulating time may be a strategy of the sex worker: engaging men in talk and thus using up time means shortening physical contact. It may be that such strategies are easier to carry out with a disabled male client, some of whom may be socially isolated and have little contact with women in a sexual context. Thus, sex workers may exploit a disabled client's marginalisation, and exercise more power through such encounters. Most male participants feared this strategy and those who had experienced it, such as Kadeem, interpreted it as manipulation and dishonesty.

A ‘bad’ sex worker was also positioned by many to be criminal (even though only one participant had experienced criminality within his purchase when he was robbed) and rejecting. Perceiving rejection (based upon their impairment and non-normative embodiment) by a sex worker was more common among participants and was narrated as very painful by those who had experienced it. For example, Mark (who had been rejected more than once) said that one sex worker had turned up, left upon seeing him and yet he was still required to pay a cancellation charge of £60. Equally, male participants said that accessibility was very important. Kadeem said that he went to an inaccessible massage parlour which resulted in him having a “*hand job*” in his car because he couldn’t get into the building. Not only was this not what he wanted (and meant he missed out on the included body massage), but it meant he had to take part in a risky activity; likewise, Harjit, on his first (and only) visit to a sex worker, said that he did not receive the full sexual experience he went for because the worker couldn’t move him out of his wheelchair, or move the chair to an adequate setting which would facilitate intercourse. As a result, this meant Harjit was fully clothed throughout the purchase (the sex worker unzipped his trousers) which significantly detracted from his experience.

The participants who had used what I call a ‘disability-specific service’ positioned their sex purchases as more fulfilling than those who made their purchases through typical sex markets. Internationally, in countries and states where sex work has been decriminalised or legalised, such specialist services are much more common and are often merged with sexual surrogacy services. For example, in the Netherlands, state funds have been used to provide sexual services to disabled people for over 30 years (Sanders 2010) and in New South Wales, Australia, an

organisation called Touching Base ‘brings together sex workers, people with disabilities and service providers working in the disability sector’ (Wotton and Isbister 2010: 155). While sexual surrogacy is available in the UK, it is far more prevalent in other countries, such as the USA and Denmark (Earle 2001).

The TLC Trust was used by a few participants. Its website features a list of male, female, Trans, and BDSM service providers (sex workers and massage therapists) organised by geographic location. The website also features a forum where users can discuss a range of topics and share their experiences of purchasing sex. Sanders (2008: 68) suggests that online spaces (for non-disabled and disabled purchasers) can be a ‘valuable resource for decision-making’ and also foster a sense of community among sex purchasers. Coincidentally, some participants knew each other’s stories through reading them on the site (see Soothill and Sanders 2005). The TLC Trust website strongly promotes notions of well-being, and fitting with heteronormative constructions of sexuality it emphasises an urgent necessity to be sexual, regardless of cost:

> ‘Many disabled people say that they cannot afford the fees that sex workers charge. Then we find out you have been on skiing holidays, own an expensive hi-fi, or smoke 20 fags a day. Where are your priorities? Remember, sex keeps you fit, mentally and physically. And one session with a sex worker can fuel a thousand fantasies on the nights you spend alone.’ (TLC Trust 2011)

For the participants who used the site, it had a powerful effect:

Abram: *"Um, they've got this kind of self-help thing trying to encourage people to take ownership of how they're feeling, and I was just exhausted from feeling stressed out and helpless and felt like there must be something I can do – just to change the way I feel. As soon as I started reading the website, I guess it just really legitimised the whole thing for me. I wouldn't have done it otherwise. I think I – I was more confident in contacting a sex worker from that website. I would not have known where to start my search otherwise. I mean – there's loads of agency websites but, you know, it's like a massive meat market. It certainly made me see that there were quite a few people that had used them – had come through it kind of okay – had repeated the trick. Erm, and that it didn't seem seedy or morally wrong, and I think that being able to kind of have a fairly short list [of sex workers] there was only, sort of, seven or eight. It narrowed it down and it showed each sex worker was – it wasn't going through an agency; you could contact them directly. And I just think that made it seem just more normal, as well. [...]I'd be very scared about going through an agency, [pause] I think maybe [you'd] get someone who's a mechanical get-it-over-and-done-with [type]. I wouldn't get anything out of that. I'd just be too intimidated."*

Thus, for Abram the TLC Trust website carried out a range of functions: it legitimised and normalised his desire to purchase sex; it facilitated his search and offered him a collection of sex workers who welcomed disabled clients; and it ensured his sex worker was a specialist (rather than from the standard "*meat market*" which would be "*intimidating*"). Although Abram paid slightly more for purchasing

from this specialist market, for this he had extensive online contact with the sex worker before and after meeting her which was seldom experienced by other participants. He experienced this as ensuring the genuineness of her work. Abram's interview with me took place via video messaging (Skype), meaning he was able to read the sex worker's emails to me in verbatim during the interview:

> **Abram:** [Before] *"We exchanged a few emails first. And they were just really, really positive. I've got twenty messages [laughs]. I emailed her basically saying 'I'm thirty-five, I've got [name of condition], intelligent and friendly but never had a girlfriend – never had sex; I don't even know what my sexual function is'. And, er, basically, you know 'I want you to undress me, guide my hands around your body, have a kiss or intercourse' – basically that. She replied back the day after, saying things like 'I think it's really great that you've decided to contact a sex worker. I'm really glad you contacted me. If you lived in Holland I would be free on the NHS'. [Laughs] 'Regarding disability I can see you, provide you with a very sexy, fun experience. I've only just recently started. I've not seen anyone with your same disability but I worked as a holistic therapist with disabled people'.*
>
> **...**
>
> **Abram:** [After] "*I emailed her after we met basically to say that I thought she was really incredible and I was really grateful... I said 'I can't honestly tell if I feel different today but yesterday was really fun. You helped me live out a few of those fantasies I never expected to experience. You're wonderfully affectionate, and I know that physically I*

leave an awful lot to be desired - but you made me feel pretty sexy at the time and that takes some doing. It was the most incredible privilege for me to be intimate with a human being as beautiful and sexual as you and I hope behind your professionalism you didn't find it too uncomfortable being with me. I wish you all the best in the future and I have the upmost respect for what you do, and I hope you provide lots more pleasure for many more men, especially men with needs like mine'. And, she replied back and said 'I can't tell you how much I appreciate you saying that and that I was able to make it a good experience for you. I was a bit nervous that I wouldn't live up to your expectations and I truly wanted it to be a really wonderful and comfortable experience'. She said 'I can promise you from the bottom of my heart that I didn't find you unappealing at all. Just different. You have a lovely face. You're a gentleman, lots of fun to be with physically, easy going, curious and I love that you so wanted to touch and taste me'. Um … she said it was a 'privilege to be the lady that you chose to experience sexuality with for the first time - it's an honour that will stay with me for my whole life'."

Therefore, this work was integral to Abram considering his experience fulfilling rather than shameful. Potentially, 'specialist' sex workers could provide a better service for customers by obtaining special training (currently illegal within the UK), for example, which focuses on health and safety, manual handling, and an understanding of disability and impairment (Wooton and Isbister 2010). Sanders (2007) calls for this training to be a collaboration between disability rights organisations and sex work organisations after many sex workers in her research said

they wanted more information and guidance about working with disabled customers, on a range of issues.

The professionalisation of sex work within a disability context could be argued to empower sex workers, relocating it in relation to disabled peoples' sexual politics, therapeutic intervention and sexual enablement, rather than entrenched in prevailing discourses of social deviancy/nuisance and anti-social behaviour (see Kantola and Squires 2004; Outshoorn 2001). For example, Wooton and Isbister (2010: 163), two sex workers from Touching Base, state that 'coming from a community that has often been treated with disdain, we have found it incredibly refreshing that our professionalism and dedication to Touching Base has always been highly regarded'. However, O'Connell warns that elevating particular types of sex work can ghettoise and demean others, such as those 'who give blow jobs to able-bodied men out on their stag night (sic)' (O'Connell-Davidson 2002: 93); for example, the TLC Trust website emphasises the difference between types of workers, stating 'be warned not to hire street walkers' (TLC Trust 2011).

Some argue that sex workers and their disabled clients share common political interests. Wotton and Isbister (2010: 157) state that 'the human and sexual rights of both sex workers and people with disability have often been sidelined and ignored'. Both are minority groups which experience significant stigmatisation and marginalisation and who are 'fighting for sexual rights, autonomy and freedom' (Sanders 2007: 453). However, while both are oppressed groups within society, assuming specialist sex workers and disabled men are, as one participant put it, "*making things better for each other*", denies the complex power relationships between disabled male customers and non-disabled female sex workers. For example,

Sanders (2008: 450) suggests that 'gender relationships between men and women [sex workers] when one partner is disabled may be more equal because of the marginalised status of men with impairments'. However, she also notes that that sex workers can be (physically) stronger, more sexually experienced, and, as a professional person within the context of the purchase, can occupy and utilise more power over disabled men which they may not with non-disabled customers (Sanders 2008). Furthermore, I suggest that 'specialist' sex work overlooks embedded gendered ideologies of male power whereby the female sexual body remains a commodity to be bought and sold, and its advocates fail to tackle how it, in essence, places disabled men's rights over the rights of women Additionally, on a more practical level it assumes that disabled men want this kind of therapeutic sexual service; that in a therapeutic setting, neither party can be exploited or exploitative, or violent (see McKeganey and Barnard, 1996), and that this type of service is more fulfilling ('more intimate') and therefore reduces disabled men's sexual oppression. For example, while Abram narrated his experience as comparatively different to other male participants, and positioned the context of the market from which he purchased sex as integral to this fulfilment, he later said that the fulfilment he obtained was only temporary:

> **Abram:** *"I mean in all honesty I would say maybe in the last couple of days – up until a couple of days ago – I was quite excited, quite buzzing, kind of always looking at my watch thinking, you know 'at this particular time on that date that many days ago', you know, 'this is my ten-day anniversary' or 'this is my eleven-day anniversary'. For some reason though I think that as the memory is starting to fade; again I've been*

going through a few periods of feeling a bit, kind of, down about not really knowing what the future holds. I still desperately long for a relationship."

Therefore, despite purchasing from a specialise market Abram's assertions about fulfilment of his desires were not dissimilar from those who purchased from standard markets who said they were often unfulfilled or only temporarily fulfilled through sex purchases. Other participants, even those who were initially enthused and excited about their first purchases, were unsure if they would pay for sex again:

Harjit: *"Would I do it again? Possibly, maybe, I mean, in time, maybe [...] it was a bit of a weird feeling actually, of thinking 'was that all?'"*

Kadeem: *"Then afterwards you're left feelin' crap... cos' it puts you up there in the bad category, relief for my cock, mind and heart feelin' shit"*

Mark: "*It's like being gutted I suppose, you just got sex and you actually want the whole package: A relationship, sex and everything else."*

These accounts are emblematic of the lack of fulfilment which can be experienced through purchasing sex. Kadeem indicates that paying for sex leaves him unfulfilled because his actual desires (along with many other male purchasers) were for intimacy, closeness, and feeling desirable, which the sex work context doesn't in reality provide, although it may provisionally feel like it. This finding suggests that sex work be considered as just one possibility for disabled people (Griffiths 2006; Sanders 2010); it also highlights the dangers of conflating sex and intimacy which may leave many men dissatisfied, unfulfilled and frustrated following sex purchases. As Graham stated, the context of paying for sex was largely unavoidable: *"you can't*

not be aware [that] there is a woman there because you're paying her money... you can't get away from that." As these accounts show, sex with a paid partner is limited in what it can provide; purchasing sex for participants in my research only had a temporary effect on feelings of social isolation, marginalisation, and loneliness. Moreover, this boundaried nature of sex work once again emphasises the inadequacy of rhetoric about sexual 'need', because, as men's accounts have shown, sexual fulfilment does little to solve feelings of isolation and loneliness.

Non-commercial Facilitated Sex and Personal Assistance

Unlike sex with a sex worker, facilitated sex is specific to the disability experience and impaired body. However, like sex work, facilitated sex can be 'fraught with moral complexity' (Earle 1999: 309) and 'ethical, moral, practice and policy dilemmas' (Shuttleworth 2010: 4). As participants' experiences within this half of the chapter show, facilitated sex is embedded within long-established gendered power relationships and heteronormative discourse. While it remains a significantly under-researched area of disabled peoples' sexual lives and an area where 'sexuality and disability researchers should shine a beacon' (Shuttleworth 2010: 4), there has been some attention to the legal, safety, and intimacy issues involved (Mona 2003; Earle 1999, 2001). However, there is little research from a disability perspective which explores facilitated sex through lenses of gender and sexuality, nor which reflects on the experiences of disabled people themselves in comparison to the considerable literature focusing on PA/care/support workers' experiences of 'managing' (usually) male sexuality (Thompson et al 1994). The absence of such inquiry from a disability perspective not only emphasises the controversial nature of facilitated sex within the disability community, but leaves

facilitated sex to be contextualised in other research spaces where the social and cultural aetiology of such practices are overlooked.

In terms of sexuality, facilitated sex is contentious because it contradicts the fundamental norms of conventional heterosex which advocates sexual mores which are 'heterosexual, private, ideally reproductive, and above all autonomous' (Shildrick 2009: 70). As Shildrick (Shildrick 2009: 70) identifies, 'facilitated sex – by definition – cannot be wholly private or self-directed', moving disabled peoples' sexualities further away from the heteronormative ideal and thus dressing 'their sexual practices in deviance and perversion' (Siebers 2008: 133). Importantly, Shildrick (2009: 73) points out that gay disabled men's facilitated gay sex is criminalised by the UK's Sexual Offences (Amendment) Act 2000, which requires all 'homosexual' sex to take place in private; she argues, 'clearly gay disabled sex is, strictly speaking, illegal if it is facilitated by a personal assistant whose physical presence is required'. Further to this, the same piece of legislation 'outlaws sexual activity between a disabled person and his or her personal assistant' (PA) (Hollomotz 2010: 28). This means that PAs who take part in *direct* sex facilitation (e.g. masturbating a client) can be prosecuted and would consequently be prevented from maintaining a clear mandatory Criminal Records Bureau check which is required at the commencement of each new employment contract.

However, despite the legal, ethical, and policy boundaries, 'for many disabled people, facilitated sex is an important part of everyday life' (Earle 2001: 433). Mona (2003: 212) argues that 'given that many people with disabilities often need to structure their life plans around public and governmental supports, it becomes impossible to conceptualise their sexual life experiences outside of societal

influences and socio-cultural norms'. My participants' stories of care, (all that received it, was funded by the state rather than private funds), often featured the role of the 'third person' – in this case, the personal assistant (PA). PAs played a key role for some participants' in accessing sexual pleasure, as well as the general facilitation of sexual life through a range of activities (Earle 1999); for example, pre-sex and post-sex help and support, such as preparing the disabled person for sexual activity, 'cleaning up', and providing personal care after sex had taken place (see chapter six). None of my participants said that they had received direct facilitation during sexual relations, such as physical support assisting movement during intercourse. However, for some disabled (male) participants who were not in relationships, PAs had directly facilitated their masturbation and self-exploration, and played an integral role within the purchasing of sex.

Participants' reactions to questions about facilitated sex were varied. For those who utilised PA support before and after sex with partners, this was seldom understood as facilitated sex. Instead, facilitated sex was assumed to refer only to assisted masturbation (rather than a broad spectrum of practices). Only two male participants said they had experienced a PA assisting masturbation and were comfortable speaking about such experiences. Some participants showed awareness of assisted masturbation but said that it is not something they would morally or practically consider (e.g. as it may disturb a care arrangement); others objected strongly to the practice. This difference in reactions shows that the practice is, firstly, commonly known about by the majority of disabled people who receive personal assistance, but also that this embodied form of sexual facilitation is highly contentious.

Additionally, while women's voices were largely absent from discussions on purchasing sex, they were often more present during talk about assisted masturbation. The context of this talk was largely upon advocating for the rights of PAs not to have to carry out sexual duties on behalf of male clients; and many women positioned disabled men who took part in assisted masturbation as deviant. Contrastingly, Browne and Russell (2005: 385) found that the disabled women in their research desired more awareness of their sexualities from PAs (for example, help with masturbation) and thus 'agreed that research is needed to explore gender issues, particularly in relation to the needs of women, including lesbians living with a disability'. One of my participants, Jenny, a 64 year old wheelchair user, spoke of an online discussion forum where she works as a moderator. The topic of assisted masturbation had been raised by a male member, much to the disgust and disapproval of female members:

> **Jenny:** *"The response was incredible. Some of the men seem to think that they should ask [PAs to masturbate them]...others said no. It was mostly women who said "hang on a minute, you 'know, you're looking at almost a prostitute role aren't you?" "Could you be that non-medical?" "Would you just stick you gloves on and go [mimes hand job]?" I think... what would that do for the person having it done? I mean, surely there ought to be some pleasure in it? It's violating, it's just like a medical procedure, and what would the relief be in that? I really feel for these lads that have still got all these emotional and sexual feelings and have got no way of relieving it, it must be dreadful. I do feel that. But to ask a young woman carer to come in and do it for you, I can't see that...would*

you personally do it? I know I wouldn't unless I was in love with someone. I think it's too intimate a thing to ask of another person who you're not... [in a relationship with]... I also think it's one step beyond the boundaries of a carer and I don't think many carers, if someone said, "Right, that's your job and you've got to go in there and wank him off, I mean, you're not going to do it are you? People [PAs] will be going, "Right, that's the end of that job, I'm going to go and find something else... I'm going to sell things on a market or something". I think carers are hard to come by, good carers, and starting that sort of expectation of them I don't think... but I feel the frustration of these people, men and women, it's not just men who get frustrated it's..."

Jenny's account identifies the possible lack of pleasure, sensuality, and relief within assisted masturbation carried out by PAs, and it highlights the "*violating*" and "*medical*" context as highly problematic and both contradictory to intimacy and harmful (see Shakespeare et al 1996). Her account is gendered, resembling typical heterosexual romantic scripts; for example, she talks about love, intimacy and (emotional) feelings in relation to sexual pleasure, characteristic of normative femininity. However, while Jenny did (along with other female members) chastise disabled men's actions, her account equally reveals empathy for the "*lads who have all these sexual feelings*" which simultaneously implies that the desires of young disabled women are less important (although she later goes on to include women when talking about desire and frustration). Most importantly to Jenny, is her concern that sexual facilitation goes beyond appropriate boundaries of the professional relationship, and that movements towards facilitated sex being expected of individual

PAs, which is part of the emphasis upon 'holistic care' (Earle 2001: 434) within contemporary nursing movements, is that this may lead to the loss of good PAs.

The Role of the PA in Sex Purchases

For many male participants who had purchased sex a PA was integral to a successful purchase. Despite the fact that they were all able to research, negotiate and arrange their own purchase without needing help from their PA, PAs did fulfil a variety of other functions related to the purchasing of sex, such as: helping a man decide whether or not to purchase sex; attending to privacy issues; arranging money; answering the door; offering moral approval and support; ensuring safety; preparing his body; creating an environment conducive to sex; and, for one male participant, assisting in a crisis that occurred. In addition, several participants also talked to their PA about their experiences (post-purchase), which they could not do with family and friends. The role of the PA was largely dependent upon the severity of impairment of the participant. Without this crucial support, several male participants with severe impairments may not have had the opportunity to purchase sex. This highlights that, while there is a significant deficit in statutory and voluntary support services recognising disabled peoples' desire for sexual expression (see Wotton and Isbister 2010), this deficit does not extend, as this section suggests, to individual PAs who were fully supportive of their clients' wishes and central to sex purchases taking place.

Abram saw his (male) PA as crucial to his decision to purchase sex. Prior to purchase, Abram said that he had discussed sex work with his PA. Not only did his PA's lack of surprise confirm to Abram that his desires were not inappropriate or out of reach, but his PA, as someone who knows Abram's body and its capabilities

intimately, offered helpful advice about the possible physical practicalities of the sex purchase. So important was his PA's approval that, if it had not been present, Abram said that he would not have gone on to purchase sex:

> **Abram:** *"I don't think I'd want to disrupt my relationship with him. Life's complicated enough without causing a scene with someone you live with day to day. With his support, I decided that yeah – I'd go through with it."*

Abram's assertion here reveals the difficult power dynamics which can occur within the relationships between PAs and disabled people. For example, in order for Abram's desire for sex to be fulfilled, the (moral) sanction of his PA was crucial. Shakespeare et al (1996: 38) suggest that 'PAs have a responsibility to ensure that assistance is exactly that, assistance, and that no judgements are made about the nature of the assistance required' – thus there is the possibility that the approval Abram's PA offered was performed. However, this is problematic in that when it comes to matters of sexual life – particularly commercial sex – PAs do have the right to object and thus not facilitate, making the disabled person's access to this form of sexual expression dependent upon the consent of another person who may not be willing to support it. In her research, Earle (1999: 312-313) found that PAs made 'moral judgements' and behaved in ways which did not 'benefit or support the person they are working for'; thus sexual support, for some, was withheld (see also Browne and Russell 2005). In contrast, while my participants saw their PAs as supportive and obliging, this still meant sexual agency could not have been achieved without the support of a PA, illustrating a dependency within sexual life. Should his PA have objected, Abram could have requested another PA, but his account here

(and wider story) indicates that this settled relationship is not only vital to his daily functioning, but also that, because his PA lived with him he had become as much a friend, companion, and housemate as a contracted worker. Thus, not wanting to "*disrupt the relationship*" is as much based on maintaining personal relations as professional ones, showing the complexities of the caring relationship and the impact this can have upon sexual expression.

In addition to providing moral endorsement, PAs were essential to male participants' preparing themselves and their bodies for an encounter:

> **Mark:** *"'I can spend whole days dedicating them to prostitutes, like don't drink a few hours beforehand, don't eat too much 'cause it makes my heart beat fast so…I try to get my PA to make my flat a bit cleaner, help me with washing, make sure that if I do pee, to wash myself afterwards, make sure there's no trace of pee, and spray some perfume on me, on the sheet."*

The above set of practicalities – which Mark called his "*ritual*" – was important to him feeling comfortable and confident, particularly in terms of how he looks and smells. Mark and Abram each said that PAs would undress him (or put him in loose clothing which could be easily removed) prior to the sex worker arriving so that she did not struggle with moving, handing, or undressing him. Sanders (2007) found that sex workers with disabled clients welcomed this PA assistance. According to Mark and Abram, PAs also had to answer the door, welcome the sex worker, and escort the sex worker into the bedroom. PAs were also useful for obtaining the money to pay the sex worker and for safety during the purchase:

Abram: *"I basically told [PA] to shut the door, shut my door, ask her to wait for a moment in the living room and say to her 'okay, you can come through in a moment'. Then she came in – kind of, sort of, laughing, 'hi'. She was laughing at the fact that [PA] had just looked at her and said 'he's all yours' [laughs]."*

Terry: *"Erm, there is ways of safeguarding – by, you know, having a PA nearby who can see what's going on inside."*

Having a PA close by could also be needed in case a crisis arose. Abram said that during the sex worker's visit, his (electric) bed broke and his PA had to step in and mend the bed before it could continue.

Abram's buying of sex has led him to think about how much he wants to have control over his care arrangements:

Abram: *"I think I would be a bit more specific now about my requirement on a carer [PA]. At the moment he comes from an agency that the social services fund directly. And that's my choice, because I didn't want to get into this whole Direct Payments business. And maybe I don't need to immediately change to Direct Payments in terms of employing my new people, but maybe there'll come a point when I do, just so that I can be sure that I'm getting people that are cool with these sorts of choices. How I would bring it up I don't know. Obviously my dad would be involved to some degree in making sure that I had carers [PAs] sorted out. I'd like to think that I'd interview them myself completely privately, but – yeah, it's the sort of thing where I don't think you can put*

much down on paper – and kind of contract it, so … But yeah, I definitely feel like I need to explore a lot more about myself. And I want these carers to understand too, to help me with that."

Mona (2003: 217) suggests that 'one of the most integral parts of receiving assistance with sexual expression is identifying a PA who is comfortable with assisting these activities'. Abram's account reveals that, even under the Direct Payments system (where recipients receive government funds and broker their own personal assistance), reaching a joint understanding with the PA about the expectations of care may still be complicated (see Glasby and Littlechild 2009). Agreeing to facilitate sexual life via supporting sex purchases is, currently within a UK social care context, not something that can be put into a formal Care Plan despite the fact it is the norm in countries such as the Netherlands where the government can fund sexual services for disabled people. New approaches to UK social care, in particular, the *Personalisation Agenda*, where (in theory) service users now write their own Care Plans (though they still need the approval of a social worker), may further enable disabled people to include sexual fulfilment as part of their personal and social 'goals' within the Plan. However, the prevailing asexualisation of disabled people, including 'professional neglect of disabled sexual identities' (Earle 2001: 433), as well as the perceived ethical ambiguity of commercial sex transactions, is likely to continue to make such desires difficult to voice, particularly in a welfare context.

Assisted Masturbation

Existing research shows that PAs can be very unsure of how to deal with the sexual desires of their clients (Whyte, 2000; Browne and Russell 2005) this is despite 'problems with managing men's sexual behaviour' (particularly of learning disabled

men) being well identified within a care context (Chivers and Mathieson 2000: 75; Thompson et al 1994). Negotiating the assistance of a PA with masturbation – either through supporting a man's hand on his penis, or masturbating him – could be fraught. While Kadeem saw his PA masturbating him as a regular, unproblematic arrangement – "*when it gets to a couple of weeks and when it gets too much she [PA] just does it for me"* – Abram's story revealed just how contentious the negotiation process could be:

> **Abram:** *"I miss having female carers now for company and … [pause] I mean, sexually as well. I mean there were times I used to try and judge how the female carers would be towards things like masturbation, things like that …"*
>
> **Kirsty:** "*How did you do that?*"
>
> **Abram:** *"I would try and just ask for help to different degrees. And just see how they would react. Some of them were actually very good like that and didn't seem to have a problem. Erm … a couple of them did get offended by it..."*
>
> **Kirsty:** *"So some of the carers obliged?"*
>
> **Abram:** *"Yeah. I mean one of them – she was a young German girl. We had people from all over the world. And she's the one that stands out as a person that genuinely wanted to help as much as she could. And, erm, up to the point where, if I wanted to masturbate, she would pull back the foreskin, put my fingers on my penis and … She seemed quite – she didn't seem to have a problem with doing that at all. So that was good for me.*

And a couple of the other people were okay, you know, just to put my hand down there and – you know."

Kirsty: *"So they would facilitate?"*

Abram: "*Yeah. And other people [PAs] were kind of doing it but very kind of reluctantly..."*

Abram's account clearly illustrates how problematic (and risky) situations where he *"sees how they react"* can be, and his description of PAs as "*doing it reluctantly*" reveals the complexity of the situation. Jeffreys (2008: 333-334) states that facilitated sex constitutes 'a form of unwanted and potentially highly distasteful activity within the ordinary expectations in male dominated societies that women should be accessible to men and sexually service them' and a practice whereby disabled men 'demand masturbation from poor migrant women who will be in no position to defend themselves against demands by their clients for such services' (see also Raymond 2004). However, rather than the belligerent 'demand' that Jeffreys suggests, Abram describes his negotiation for assisted masturbation as perilous, precarious and potentially highly embarrassing. Browne and Russell (2005: 381) report many participants (particularly female ones) in their study were 'too shy to ask' for help with masturbation, but said that it 'would be a great relief if they could feel comfortable enough to ask carers to help them to masturbate', suggesting that it may be a practice that is desired by women far more than it is demanded.

While Jeffreys' (2008) radical feminist writings on disabled sexualities are, I argue, inherently ableist, in that they overlook the complexities of disabled sexualities and impairment, the extent to which assisted masturbation and facilitated

sex more generally are embedded in gendered ideologies and relations of power must be recognised. The male sex drive discourse (Hollway 1994), for example, means that PAs may be more likely to offer this service, or reluctantly agree to it, based on socially constructed gendered ideas of male 'relief'. Chivers and Mathieson (2000: 75) argue that conventionally gendered discourses of assisted masturbation are reproduced in PA training and practice: 'staff may consider that young men need sexual release and therefore plan to teach about masturbation; but rarely are young women's sexual needs considered within an individual planning process'.

Further highlighting the highly gendered nature of assisted masturbation, such experiences were completely absent from female participants' care stories, either because women did not speak of it, or (perhaps more likely) because, like with sex purchasing, these avenues of expression weren't open for disabled women. This absence speaks volumes. Such services are likely seldom offered to disabled women (by either male or female PAs) because there is assumed to be less of a (physiological) 'need' for 'inert' female sexualities (Chivers and Mathieson 2000). Nor are they requested by disabled women due to possible conflicts with dominant notions of feminine sexuality as passive, coy, and modest and female desire as embedded within romance. In particular, male PAs are less likely to offer assistance with masturbation to disabled women (than female PAs are to disabled men) based on constructions of disabled women as vulnerable to sexual abuse and constructions of male PAs as abusers. Thus 'concern with the risk of sexual abuse and exploitation may go some way to explain this neglect' (Earle 2001: 436). Another reason the practice is more common between female PAs and disabled men is because of the PA's identity as female and thus as a pleasure provider; for example, disabled men

did not talk of making such requests from male PAs. While this may have been about not disturbing heterosexual masculine performances, or the fact that the care industry is made up predominantly of female workers, it also demonstrates that the act itself is not purely mechanical (otherwise it wouldn't matter who 'did it') and thus that the (female) gender identity and body of the PA is central to the practice taking place.

Blurred Boundaries

While relationships between disabled men and their male PAs were very much platonic and based on typical male friendships, for some male participants this was not the case in relationships with female PAs, and such relationships were considered potential sites of sexual relationships. This is possibly because, as I have shown in other chapters, the PA/disabled person caring relationship can have blurred boundaries. For example, Browne and Russell (2005: 386) found that PAs and disabled clients had 'different understandings of what is 'work' and what is 'personal' and that these blurred boundaries offered their participants the 'benefits' of 'carers [that] provide assistance with masturbation'. While Neal (1999) argues that it is the responsibility of the professional to maintain boundaries in care relationships, many of my participants (men and women) stipulated that maintaining boundaries was equally their responsibility, as found in similar research (see Browne and Russell 2005). This was, by many, emphasised when it came to matters of sexuality; for example, one male participant said of his relationship with his female PA: "*It is not sexual, and carries no ulterior motives or emotions other than to get a job done".* However, other male participants found it difficult. For example, while Mark asserted strongly that he doesn't "*ask for them [PAs] for extra [e.g. a sexual*

service]", he did say that he regularly fell in love with female PAs and that employing them was a primary way for him to meet women:

> **Mark:** *"I used to think that a way of getting a girlfriend could be to get a few up from the agencies [female PAs] and then you fall in love etcetera and everything else... [...]Ok, falling in love is a natural thing but, this is 3 different girls [PAs]….and I fell in love with each one… but I guess… sometimes I get so desperate, like really searching for a girlfriend, that I look for the easiest way to get a girlfriend and try to get enough contact [with PAs] and [then] maybe something [may] happen [...] I guess you hope that it means something more than just a physical task and that they'd have the same feelings as well…."*

"*Getting a few up from the agencies*" shows Mark's attitude as an employer (similar to the power as a sex purchaser) and the ways in which power can be used to objectify personal assistants. This strategy has been found in other research; for example, Browne and Russell (2005: 384) report one of their participants 'specifically hired carers around his own age, making attraction 'more likely''. The contested meanings of the "*physical task*" (e.g. washing, bathing etc) add to the ambiguity of the relationship for Mark: the carrying out of such tasks has more of an embodied and sensual meaning for him than for a PA, to whom Mark's body may be merely a site of work. It also echoes, from the previous section, the desire for the sex workers to be "genuine", for the meaning of the work to go beyond a job or financial transaction. Thus even where facilitated sex and assisted masturbation *aren't* present, the male/female caring relationship can still inscribed with typical gendered

heterosexual scripts. To avoid this situation Mark stressed that he now only hires male PAs.

Kadeem, (and a couple of other male participants), also said that they could obtain sexual pleasure from a PA's touch during routine personal care: *"it can feel too good sometimes".* Similarly, Kadeem said of one female PA who assisted him in masturbation that she "*looked like she was getting turned on*" when carrying out the act, but that another deliberately avoided washing his genitals because he would get an erection (suggesting that she wasn't comfortable with this reaction). Feeling pleasure and embodying the routine touch of a PA shows that the customary 'body work' carried out by PAs is a contentious space of multiple meanings of which the PA may have little control. Wolkowitz (2006: 147) defines body work as 'employment which takes the body as its immediate site of labour, involving intimate, messy contact with the (frequently supine or naked) body, its orifices or products through touch or close proximity'. However, Siebers (2008: 145-146, original emphasis) states that 'as long as staff *act* professionally, they do not consider themselves responsible for sexual side effects, and yet they cross erotic boundaries constantly, with little regard for the consequences of their actions'.

Moreover, recent changes to disability policy (*Personalisation Agenda* and *Individual Budgets*) may impact upon the potentially difficult boundaries between PAs and disabled people. Such changes position disabled people as purchasers of their own care and thus, in many cases, direct employers of their PAs. This empowerment is of particular concern if an employment contract is dependent upon assisting masturbation. As one male participant admitted, whether he hired a PA or not was based on her willingness to carry out masturbation and her level of

attractiveness. Furthermore, the disabled person as the bearer of the money a PA earns may also have an impact because money is, as Zelizer (1989: 343) argues, 'interdependent with historically variable systems of meanings and structures of social relation'. Thus, far from being a genderless commodity, money has links with masculinity and masculine power (Zelizer 1989); for example, men's labour has a higher value within the capitalist system (Williams et al 2010), making 'wealth relatively masculine' (Williams et al 2010: 17). The majority of money for care provision now being brokered and funded by disabled people themselves (via an Individual Budget) rather than the state, specifically to foster disabled peoples' empowerment, precisely recognises that money brings social value and power. This, combined with the notion that disabled people may prefer more informal paid caring arrangements and unqualified and unskilled workers who can be trained to meet their specific needs and requirements, as Morris' (1993) found in her research, may increase arrangements whereby there are no employment contracts meaning PAs within such arrangements have little or no employment rights (Ungerson 1997).

Conclusion

To conclude, this chapter has shown how participants' experiences of commercial and non-commercial facilitated sex are problematically entrenched in dominant gender ideologies, heteronormativity and heterosexuality. The general acceptance of the marginalisation of disabled women's experiences, both from debates about the place of forms of facilitated sex for disabled people, and from such practices themselves, reveals the extent to which these remain highly gendered practices. Women's absence also shows the way in which such practices *reproduce* a heteronormative sexuality which is predicated on a mode of sexuality that requires

female passivity and asexuality, meaning disabled women are largely unable to act in the same way. However, rather than making the case for increased access to similar sexual activities for disabled women, which fails to account for the very nature of heteronormativity and risks inadvertently endorsing heteronormative frameworks that aren't really working for anybody (as the rest of my thesis argues), my analysis shows that disabled men are more able to locate themselves within normative masculinity through such heteronormative narratives and practices (although this is a fairly precarious identity that is easily disrupted).

Moreover, my analysis has shown that male participants' experiences of purchasing of sex and sexual surrogacy were not perceived to be a male 'need' for sexual gratification, echoing findings from research with non-disabled men (Sanders 2008; Campbell 1998). Instead, it was found that male participants articulated multiple and complex reasons for their sex purchases which were, for the most part, shaped by both their social and political positioning as disabled men *and* – as with the motivations of non-disabled men – by hegemonic masculinity and dominant notions of normative sexuality. For example, male participants' motivations were to gain sexual experience or sexual skills, the learning of which they felt they had lacked through exclusionary adolescent cultures (see chapter three); to invigorate and sexualise the *unnatural* sexually 'defunct' male body; to feel sexy through particular kinds of sexual action; to have experience to contribute to male sex talk (see chapter three); to express agency and resist oppressive familial control; for "*a different type of sex"* that privileges non-reciprocal pleasure, and because paying for sex was *easier*. Thus these motivations (or justifications) are located in the nexus of disability *and* masculinity.

Furthermore, analysis of male participants' interactions with sex workers has revealed the complex power dynamics between disabled male sex purchasers and non-disabled female sex workers. Data showed that sex workers may deploy greater power in their work with disabled clients (in comparison to non-disabled customers) because of the 'vulnerability' of some disabled men in this context (for example, men reported criminal activity and theft, rejection, manipulation of time, fees, and poor quality of service). However, through their role as a consumer of commercial sex, male participants could claim considerable power over sex workers, often in similar ways to non-disabled male customers. For example, this could be through scrutinising their physical bodies, or denigrating their racial ethnic groups, social background, femininity and chasteness; through disobeying set contract rules; and expecting, (without wanting to pay), 'genuine' effortful work requiring the appearance of the suspension of a worker's own identity and subjectivity. Therefore these findings undermine discourses which position disabled men solely as sexual victims, stripped of male power because of their marginalisation from hegemonic masculinity, and suggests that their disabled identity and impairment doesn't entirely erase their male power or sexual opportunity within a commercial context. Equally, finding challenges disabled peoples' campaigns for sexual citizenship which are based upon seemingly gender neutral notions of disabled sexualities and sexual politics.

While there was considerably less data surrounding non-commercial facilitated sex, the gender dynamics of personal assistance, particularly where more embodied forms of facilitation such as assisted masturbation take place, cannot be ignored. Just as sex workers and disabled people are both from oppressed minority groups

(Wooton and Isbister 2010), so too are disabled people and care workers/personal assistants, thus 'both purchasers and providers are poor and/or vulnerable to exploitation' (Ungerson 1997: 50). Despite this, disabled men could occupy considerable power in their role as a PA employer, and practices of assisted masturbation were significantly shaped by their male identity. Similarly, my analysis has shown that personal assistants can have a key presence within the sexual lives and sexual expression of disabled men, which can include facilitating sex purchases, providing sexual 'relief' in the form of masturbation or assisting with pre and post-sex support. This is of undeniable importance for the disabled people who may not be able access sexual pleasure and expression without such support. Thus, I have suggested that the support of a PA can act as a double-edged sword for such disabled people whose sexual expression is dependent upon the moral scruples and personal autonomy of an assistant (see Earle 1999; Russell and Browne 2005).

Therefore, I argue that disabled people are seldom degendered within commercial and non-commercial contexts, as they are in other spaces. Rather, disabled participants' gendered identities, and associated oppressions, are a variant of prevailing gendered discourse which both empowers and restricts the sexualities of (non-disabled) men and women. Because discourses of sexual rights and 'needs' are gendered in ways that privilege men's constructed sexual 'need' and deny women's sexual agency, they legitimate men's opportunities for taking part in commercial and non-commercial facilitated sex. In contrast, neither the women nor men in my study were able to articulate the rights of disabled women to access this form of sexual expression. This is partly because female sexuality is so tightly

constructed around romantic desires which exclude commercial sex, that there is an absence of any substantial market in commercial sex work for women.

Conclusions

Introduction

> ‘Writing this book, we have tried to perform a balancing act. On the one foot, we have had to discuss the oppression and marginalisation experienced by disabled people, the barriers, the prejudice and the abuse. On the other foot, we have wanted to give a positive account, celebrating the resistance of disabled people, the delight and the joy of disabled peoples’ sexual and emotional lives, the essential ‘normality’ of the disability experience. Some disabled readers will think our approach too optimistic – others will think it pessimistic and grim’ (Shakespeare et al 1996: 209).

In drafting this conclusion, I, like Shakespeare and his colleagues, must confess that the ‘story’ that emerges from my research is not one I expected (nor wanted) to tell. Perhaps borne out of my own disability experience and activism, or perhaps out of a politics of hope, I wanted to find (and ‘prove’) that disabled participants were sexually agentic, cogent and authoritative in the face of ableism, and that, even though their sexual identities can be denied and suppressed in ableist culture, that this exclusion from normalcy could give birth to utopic, subversive and queer sexualities not bound by the governing institutions of heteronormativity, heterosexuality and normative gender categories, which oppress all people. Instead, my thematic analysis of participants’ sexual stories has, in revealing the complex and variegated relationships between disability, impairment, sexuality, and gender, shown that disabled participants experience substantial sexual oppression, have to carry out extensive forms of work within in a variety of spaces and interactions, and that many

experience extensive psycho-emotional disablism – 'the socially engendered undermining of psycho-emotional wellbeing' (Thomas, 1999: 60) – as routine within their sexual and intimate lives. I state this here not to detract in any way from the sizeable resistance, strength, and defiance that my participants have shown, but because it is precisely at this nexus between desired and actual findings that interesting distinctions can be made. Thus, the story this conclusion tells is far more multi-faceted than my original presumptions. Through this concluding chapter, I initially draw together the main findings presented within and across different chapters (see summary of key findings below) and then locate these in both the wider contexts of disability, impairment, sexuality and gender, and existing theoretical and empirical research and knowledge of disabled sexualities. In doing so, I show where my research and its findings make a contribution to knowledge.

Summary of Key Findings

In this initial section, I provide a brief summary of key findings. This not only acts as a 'road map' for the reader, setting the scene before findings are explicated in greater detail throughout the remainder of the chapter, but more importantly shows the ways in which my key findings provide answers to my original research questions.

Research Question 1: How do disabled adults experience sexual opportunities, identities, and intimate relationships?

Heteronormative Sexuality as Disempowering Disabled Men and Women

- Heteronormative sexuality was experienced by my participants as much a form of oppression in their lived experiences of sexual life as the routine ableist

constructions of asexuality and sexual inadequacy cast upon their lives and bodies.

- Normative gender categories and normative heterosexuality were upheld and privileged by participants as given, natural and fixed, leaving space *only* for disability and impairment to be conceptualised as disruptive and highly conflicting to a heteronormative sexual life.

- There were very complicated and contradictory implications of heteronormative discourse for disabled men and women.

Heteronormativity, Masculine Privilege and (Disabled) Male Power

- Heteronormativity was found to create different outcomes and opportunities for (disabled) men and women. Thus, heteronormativity, as a male-serving discourse, worked *for* disabled men through spaces where it did not for disabled women.

- In addition, male participants generally had more manoeuvrability within, as well as opportunities to negotiate, normative sexual and gender identities than female participants.

Impairment as Part of the Experience

- For all participants, experiences of sexual opportunities, identities, and intimate relationships were mediated by the lived experience of impairment. Impairment, for the most part, was the primary means through which disabled participants conceptualised their sexual and gendered selves.

- The 'hard physical realities' (Wendell 1996: 45) of impairment were very important to participants and had significant impact upon the ability to engage in sexual encounters.

- However, many participants managed the bodily realities of impairment through devising management strategies which ensured that their bodies could be sites of sexual pleasure and enjoyment.

Research Question 2: What strategies do disabled adults employ in order to manage and negotiate their sexual lives?

Managing and Negotiating Sexual Life

- Analysis has illustrated the 'complex invisible "work" performed by disabled people in every day/night life' (Church et al 2007: 1). Participants carried out a variety of forms of work, negotiation, and management within multi-farious spaces of their private and intimate lives.

- Participants' labour was diverse and served a variety of purposes within the construction of the sexual self.

- Much of participants' work and labour was rooted in, and thus indicative of, the oppressive and inherent inequalities of ableist culture.

Research Question 3: What are the psycho-emotional consequences of ableist constructions of sexuality for disabled people, and what are the psycho-emotional consequences of their own strategies?

- Participants were Othered and desexualised through heteronormative discourse, and were denied autonomy, agency and sexual freedom through their engagement with particular ableist social institutions and an ableist cultural imaginary.

- Psychoemotional disablism was experienced through a variety of 'known agents' within disabled peoples' own networks (Reeves 2002). Participants reported being bullied, abused, manipulated, exploited, chastised, ridiculed, humiliated and shamed in various intimate spaces.

- Through internalising heteronormative ableist discourse some participants devalued themselves and became complicit in their own experiences of psycho-emotional disablism.

- Many participants' strategies were what I identify as harmful and constituted significant psycho-emotional disablism. Additionally, much of the work carried out often involved performing to ableist 'demanding publics' (Goodley 2010: 93).

While, I have merely summarised my key findings here, they are fully explained throughout the remaining four sections of this chapter. In the first section, I begin by looking at the very complicated and contradictory implications of heteronormative discourse for disabled men and women and the means through which it was experienced as disempowering and thus, for many, constituted significant sexual oppression. In the second section, I examine the ways in which heteronormative discourse empowered disabled men relative to disabled women; for example, focusing on the ways in which male participants had more manoeuvrability within normative sexual and gender identities than female participants. In the third section, I consider the prevalence of impairment and 'impairment effects' (Thomas 2002) within participants' stories, contextualising the ways in which impairment was used by participants as vehicle through which to construct the sexual self. In the fourth section, I consider the strategies participants employed in order to manage and negotiate their sexualities and the psychoemotional consequences of such strategies; and I question what this work means in the context of the disability experience and sexual life. Importantly, throughout this final chapter I discuss participants' experiences of psycho-emotional disablism in the context of my other findings in various locations (rather than in a sole section). This is in order to show the ways in which psycho-emotional disablism was typically embedded and produced within and through participants' lived experiences of sexual and intimate life.

Heteronormative Sexuality as Disempowering Disabled Men and Women

An unanticipated finding to come out of my research was the extent to which normative heterosexual discourse, as a central tenet of ableism, was deeply oppressive for my participants and therefore impacted considerably on their

experiences of sexual opportunities, identities, and intimate relationships. For example, the psycho-emotional consequences of heteronormative discourse were extensive: participants were routinely Othered, desexualised, denied autonomy, agency and sexual freedom through an ableist cultural imaginary which propagates oppressive constructions of impairment, normative embodiment, disability, and disabled (a)sexualities, thus influencing, as Shildrick (2007: 221, original emphasis) argues, 'the contested question of who is to count as a *sexual* subject'. Another psycho-emotional consequence was experienced through internalising ableist heteronormative discourse. For example, participants devalued themselves, something Reeve (2008: 1) calls the 'barriers in here', and thus became complicit in their own experiences of psycho-emotional disablism. Devaluing the self, particularly in relation to the non-disabled Other, was part of the disabled (sexual) psyche for most participants; low sexual self esteem and self-worth, feelings of inadequacy (in relation to heteronormative discourse), and low body confidence were common and constituted significant psycho-emotional disablism. This could impact upon participants' formation of a positive sexual self, as well as the deployment of strategies to negotiate and manage sexual oppression.

In retrospect, none of my original research questions even referred to heteronormativity or heterosexuality and this was because my original conceptualisation of sexual oppression was primarily as a form of disablism, rather than ableism. By this, I mean that my original focus was upon disabled peoples' sexual oppression as amounting to management and resistance of the ableist constructions ('negative' sexual stereotypes) of disabled sexualities which deny them sexual agency and autonomy and oppresses their sexual identities and subjectivities

(Hooper 1994). While I understood these constructions as rooted, at least in part, in disabled peoples' *exclusion* from notions of sexual normalcy, my analysis has revealed sexual oppression to be far broader; thus ableist sexual normativity, or sexual ableism, was the root cause of (sexual) oppression, of which sexual disablism is just one part. Thus, as well as experiencing a sexual oppression specific to the impaired body and disabled identity (being marked as a sexual Other through 'negative' sexual stereotypes), disabled participants also experienced an acute form of the sexual oppression we all experience as actors within heteronormativity and heterosexual desire and practice. Therefore, *inclusion* in heteronormative discourse was as oppressive as *exclusion*. This, I argue, constitutes heteronormative sexuality being experienced by my participants as much as a form of oppression within their lived experiences of sexual life as the routine ableist constructions of asexuality cast upon their lives and bodies. This finding affirms Goodley's (2010: 157) notion that 'in order to analyse disablism we need to be mindful of the complementary hegemony of ableism', and supports Campbell's (2009: 4) argument that disability scholarship and its researchers must 'shift our gaze [from disability] and concentrate on what the study of disability tells us about the production, operation and maintenance of ableism' which is, argues Wolbring (2008: 253), 'one of the most societally entrenched and accepted isms'.

Participants' sexual stories privileged normative sexuality as a central theme, showing that 'a significant amount of storytelling that masquerades as disability is not really about impairment or disablement, the 'real' story being told is about ableism' (Campbell 2009: 197). For example, participants' stories showed the sizeable extent to which normative gender categories and normative heterosexuality

were upheld and privileged as given, natural and fixed. For all participants, intimate relationships and coupledom were strongly desired and served to confirm worth and desirability; sexual expression and gratification was understood as natural (particularly by men) and obtaining it served to proffer social value and humanness and 'constitute full subjectivity' (Shuttleworth 2000: 280); normative bodily aesthetics were revered (particularly by women); and the prescribed 'mechanics' of heteronormative sexuality remained the fixed norm from which other alternative sexual methods and pleasures were judged.

Importantly, the privileging of sexual and intimate normalcy bore significant weight on participants' experiences of sexual opportunities, identities, and intimate relationships because it *only* left space for disability and impairment to be conceptualised as disruptive and troublesome to meeting heteronormative ideals. Thus, the realities and practicalities of the impaired body and the socially constructed desexualised disabled identity were experienced by participants as highly conflicting to a heteronormative sexual life. But, this seldom negated their desire to attain heteronormative standards. Although participants did not perceive heteronormative discourse as oppressive, their sexualities, selves, identities and relationships were imbricated within and defined through heterosexual and heteronormative discourse despite being, as disabled people with impaired bodies, excluded from such discourses. This illustrates that while heteronormativity can and does serve to exclude those who do not fit its prescriptive criteria, it continues to shape the sexual subjectivities of, and have psycho-emotional consequences for, the excluded, as found in other research; for example, on female sexual dysfunction

(Cacchioni 2007), people with impairments (see Gillespie-Sells, Hills and Robins 1998), and people with HIV/AIDS (see Dune and Shuttleworth 2009).

Participants' experiences of sexual opportunities, identities, and intimate relationships were also mediated by complex and contradictory relationships between disability, impairment and heteronormative discourse. These were shown through the experiences of participants who – in certain spaces – negotiated gender categories and transgressed the strict boundaries of normative sexuality *at the same time as* upholding these boundaries as natural and normal through conceptualising these breaches as Other; rather than the opening up of 'new (sexual) horizons' (Shildrick 2009: 36) or 'broadening sexual behaviour' (Siebers 2008: 136). Accordingly, my participants did not label or conceptualise the breaching of normative boundaries as such, causing the meaning of this disavowal to represent (to them) little else but the Other. Existing research has also demonstrated the complexities of the impaired body and heteronormative discourse, but has largely reported disabled peoples' experiences as having positive meanings to them (see Potgieter and Khan 2005; Guldin 2000; O'Toole 2000). Thus, such findings serve as an interesting comparison to the extensive psycho-emotional consequences experienced by many of my participants. For example, in her research on the ways in which disabled people self-claim sexuality, Guldin (2000: 234-235) found that participants' assertions about orgasms 'demonstrate that they do not reject cultural notions altogether, indeed, in some cases they accept those meanings and values, more common, however, was for them to redefine how orgasms might be interpreted or experienced relative to their own bodies'.

Guldin (2000: 237) asks the difficult question, of 'who defines sexual resistance and who defines a political act?' Both disabled participants' exclusion from and transgressions of oppressive sexual systems did not automatically equate to meanings of sexual emancipation or liberation; in both scenarios disabled participants experienced the psycho-emotional consequences of both measuring and narrating themselves and their practices as Other. I suggest that this highlights a key difficulty with critical conceptualisations of disabled sexualities which are becoming the benchmark of critical disability theories of sexual life, (and to which I have expressed caution in earlier chapters). For example, proposals of a dismodernist sexual future, whereby sex, eroticism, and desire 'look very different in a "dismodern" world where cosmopolitanism, interdependence and a reliance on technology are the "norm"', and where 'dis/abled bodies will become "sexy bodies"' (Rembis 2010: 59) (see chapter two) may propose alternatives to ableist heteronormative and heterosexual systems, but these alternatives are simultaneously grounded in the political and the will to resist. This is, then, a highly problematic notion to the largely apolitical stories and sexual selves of disabled men and women in my research. By this, I mean that participants' sexual identities or practices were not, for the most part, deliberately or knowingly subversive, nor contextualised as political acts. Rather, their experiences of sexual life were determined through experiences of impairment and interactions with normative heterosexual discourse. As Guldin (2000: 237-238) says of her own findings, 'all four men in this study were engaging in sexual acts, thoughts, or behaviours that I would interpret as political, yet they would say they were simply living their lives of which sexuality is a part'. Thus, to consider non-normativity and transgression as resistance when this is not the meaning it had for disabled participants is to shroud these disabled sexualities in

a form of essentialism whereby 'the meanings claimed by the individuals themselves are lost or altered' (Guldin 2000: 237) and where the disabled voice remains unheard.

Heteronormativity, Masculine Privilege and (Disabled) Male Power

Participants' experiences of sexual opportunities, identities, and intimate relationships were also organised by the differential sexual power that heteronormative discourse afforded disabled men and women. Thus, my analysis showed that heteronormative discourse not only significantly disempowered disabled men and women, but empowered disabled men relative to disabled women. The fact that heteronormativity is a male-serving discourse meant that it worked *for* disabled men through particular means and spaces where it did not for disabled women, and thus created different outcomes and opportunities for (disabled) men and women. The conventionally gendered underpinning of heteronormativity posits women as sexually passive and men as sexually domineering. Thus, many disabled men were sexually dominant and exercised more sexual agency because of their increased access to sexual power that masculinity, heterosexuality, and heteronormativity – as male discourses – provided. Therefore, my findings demonstrate that where heteronormativity creates different sexual opportunities and identities for non-disabled men and women, and proffers non-disabled men more sexual power and dominance, the presence of disability and impairment had a lesser effect upon normative gendered discourse in relation to (sexual) power for disabled men and women than is proposed in the literature (Shakespeare 1999; Tepper 1999).

While male participants enacted and embodied a variety of masculinities within their stories, my analysis showed that disabled male participants generally had

more manoeuvrability within, as well as opportunities to negotiate, normative sexual and gender identities than female participants. Shakespeare (1999: 61) rightly asserts that:

> ‘Disabled men do not automatically enjoy the power and privileges of nondisabled men, and cannot be assumed to have access to the same physical resources. Moreover, masculinity may be experienced negatively in a way which is rare for heterosexual non-disabled men, although it could be argued that many non-disabled men also cannot attain, or actively reject, the assertive and physically dominant style of conventional masculinity’.

My findings muddy the water of Shakespeare’s masculinist suppositions. While he is right that disabled men, due to their impaired bodies and disabled identities, experience significant marginalisation within (hegemonic) masculinity, my research has shown that marginalisation from dominant gendered sexual categories served (for some) as an opportunity to negotiate gender within sexual identity and practice. For example, as seen in chapter six, some men resisted and rejected the oppressive requirements of hegemonic sexualities (such as phallocentrism and a dominant gendered sex role) and accessed a more empowering sexual project whereby they excelled in non-penetrative practices. Gerschick and Miller (1995) call this category of disabled men ‘rejecters’, on their basis to reconstruct a masculine identity according to their own (sexual) abilities, rather than by those outlined within dominant constructions of masculinity. Additionally, as shown in chapter five, some male participants were avowed by partners to have feminine characteristics or put on feminised performances without fear of judgement, what Phillips (2010: 117) calls

‘becoming socially female’ (see Garland-Thomson 2002); and, for others (though, not all), impairment was experienced as an escape from the restrictive masculine bodily requirements demanded of non-impaired male bodies.

Significantly, women seldom experienced such manoeuvrability and remained confined within conventional sex and gender norms. The majority of female participants did not have such agency when defining – or at least narrating – their sexual and gendered selves, and their sexual stories revealed few alternatives to normative categories which they could claim. For example, as shown in chapter six, disabled women remained painfully subject to their bodies. Their non-normative embodiment by no means excused them from the objectifying discourse surrounding (non-disabled) women’s bodies and thus it had significant psycho-emotional consequences. For example, women routinely hid their bodies (from themselves and partners), felt shame and disgust at their body’s divergence from aesthetic bodily norms, and (some) carried out extensive body projects to ‘fix’ their bodies according to a normative aesthetic imperative. Furthermore, despite many disabled women desiring a more active role within sex, most positioned their impairment as the primary reason this couldn’t be achieved showing that they couldn’t negotiate impairment (to a preferred sexual role) in the same ways as (some) disabled men. Additionally, as seen in chapter seven, adhering to a normative feminine sex role meant that women were not able to avail themselves of sexual opportunities available and accessible to disabled men through the male ‘need’ discourse (Hollway 1994) (e.g. purchasing sex). The fact that commercial and non-commercial facilitated sex are entrenched within and *reproduce* heteronormative sexuality, and because there is no wider discourse for women to draw on to justify purchasing sex, means

that disabled women were unable to access this sexual opportunity. To reiterate, this is not said in support of forms of facilitated (commercial/non-commercial) sex as a viable option for disabled women (or men), (largely, because this strategy often had extensive psycho-emotional consequences for disabled men), but to highlight the ways in which heteronormativity created different outcomes and opportunities for (disabled) men and women.

These findings constitute a number of important contributions. Firstly, they offer a powerful challenge to dominant ideas of male sexuality as more impacted by impairment and disability than female sexuality (see Murphy 1990); that the intersections of cultural identities of masculinity and disability are more problematic and conflicting than femininity and disability (Shakespeare 1999); and that disability 'erodes much, but not all, masculine privilege' (Gerschick 2000: 1265). However, I note that this negotiation of gender mainly occurred where male participants rejected hegemonic masculinity, and thus negotiated gender identity according to their own terms. This wasn't always possible. This finding supports the (underdeveloped) body of literature and research on disabled men and masculinities which has illustrated that men who perceive 'hegemonic masculinity as less a total index of their desirability' (Shuttleworth 2000: 227), can, as Shuttleworth (2000: 227) proposes, 'sometimes draw on alternative ideals' which are more sexually empowering. Many of my male participants, who couldn't reject normative notions and thus felt inadequate that they couldn't enact a hegemonic sexual identity as required, experienced substantial psycho-emotional disablism (for example, talk of suicide) as a result of their inability to 'let go of restrictive notions of manhood' (Tepper 1999: 37).

Secondly, these findings reveal the similarities of the experiences of disabled and non-disabled women, who occupy analogous subordinate positions within heteronormativity and heterosexuality. This illustrates – as other disabled feminists already have suggested (Wilkerson 2002; Garland-Thompson 2002; Lonsdale 1990; Schriempft 2001; Thomas 1999; Wendell 1996; Ghai 2002, 2006; Keith 1990; Morris 1991, 1993, 1996; Begum 1992) – the need for mainstream ('hegemonic') feminism to be more inclusive of all types of women and thus broaden its contextualisation of the female experience which, while diverse, is unified by women's suppression under patriarchy and male (sexual) power. However, as Thomas (2006: 183) suggests, it is not enough for this to constitute 'exclusion by nominal inclusion' – including disabled women's experiences merely for the sake of doing so. Instead, 'more sustained analyses of the social and gendered character of disability and impairment both culturally and materially is required' (Thomas 2006: 183).

Thirdly, these findings draw attention to the intersections of disability and gender as considerably more complex than is proposed in existing literature and research where disabled men and women are positioned largely as 'striving for acceptance within normative gender categories' (Shakespeare 1999: 55; see also Gerschick 2000). The complex relationship I have outlined in this section casts serious doubt over conceptualisations of disabled people as wholly degendered. By this, I mean that while disabled people may remain degendered in the eyes of the non-disabled Other, and that this degendered identity is discursively constructed within and through certain social institutions (for example, biomedicine), disabled

participants in my research did not have, within the realms of sexual subjectivity, degendered experiences.

Finally, the different relationships of disabled men and women with heteronormative discourse affirms the importance of theorising disabled sexualities through a lens which allows a focus on gender, simultaneously reaffirming the inadequacy of the 'gender blind disability studies' (Goodley 2010: 34) rooted in the social model. This casts real doubt over the relevance of some forms of discursive constructionism – notably, Foucauldian theory – to disabled sexuality studies, where discourse, the body and power are problematically gender-neutral (see Jackson 1999), and also queer theory, which foregrounds sexuality rather than gender and thus, in doing so, neglects everyday gendered realities of peoples' lives.

Furthermore, my finding that normative gender categories played a considerable role within the lived experience of sexual life for disabled participants problematises Rembis' (2010) notion that, in order to move towards an emancipatory dis/abled sexual future, normative gender binaries must be overcome. Rembis (2010: 56) proposes that the 'problem' with current disability and sexuality research is that it doesn't work enough to 'reshape the very notion of gender, sex, sexuality, eroticism, desire, and disability, and to subvert the power relations and class structures that undergird the maintenance of these ideological constructions'. Similar to queer theory critiques of feminism wherein 'by basing itself on binary genders, it [feminism] has actually solidified structures like male/female, man/woman and masculine/feminine' (Wilchins 2004: 126), Rembis (2010) proposes that *not* moving beyond the binaries of male/female, masculine/feminine, and dis/abled serves to

reinforce the heterosexual matrix, defined by Butler (1990: 5) as 'the grid of cultural intelligibility through which bodies, genders and desires are naturalized'.

However, as my findings here have shown, normative gender categories are integral to the institution of heterosexuality – which 'serves as the organising institution and ideology for gender' (Ingraham 1996: 187) – for disabled men and women. Gender constructs are not merely lexicon but have embodied social, cultural and economic meaning (see Bordo 1993) and socially organise the lives of heterosexual disabled men and women in the same ways as non-disabled men and women. Thus, they can't merely be cast away or reshaped with ease. This is not least because, as feminist critiques of Butler's work attest, totally deconstructing gender leaves us with little else. As Thomas (2006: 181) states, the 'problem is that it ceases to be legitimate to explore the lives of ''disabled women'' because this category, like ''women'' itself, becomes a discredited modernist construct'. But, also because, as disabled other feminists affirm, it is crucial to include gender in the context of disability and impairment as a means to understand the different oppressions experienced by disabled men and women (Morris 1996; Thomas 1999). Thomas (2006: 184, original emphasis) states that 'the application of these [critical] theoretical perspectives to further developing our understanding of *gender and disability* has not yet caught up – much remains to be done' in theorising disabled women's lives'. Tellingly, Thomas (2006: 184) argues that 'feminist researchers who are not so weighed down by theoretical baggage have got on with researching and writing about the gendered realities of daily living with disability and impairment'. This is work distinguished, she affirms, 'for its ''real world'' qualities, its focus on

the experiential, and its acute sensitivity to ‘‘difference’’, diversity and the multiple dimensions of identity’ (Thomas 2006: 181-182).

Impairment as Part of the Experience

For all participants, experiences of sexual opportunities, identities, and intimate relationships were affected by the lived experience and realities of impairment, highlighting ‘the limits of social construction’ (Siebers 2008: 55). Impairment was prominent within the collective sexual story and, for the most part, was the means through which disabled participants conceptualised their sexual and gendered selves. Constructing a sexual self *through* experiences of impairment is emblematic of the ways in which knowledges of disability and impairment remain entrenched within medical models (see Thomas 2002), and how detached – even social model conceptualisations of disability – can be from the everyday experiences of disabled people. The centrality of impairment to participants’ sexual story-telling is also illustrative of the way in which dominant heteronormative discourse and conventional methods of ‘doing sex’ are avowed predominantly only through ‘the bodily’ and thus remain inherently of the flesh (Tiefer 2001).

In terms of the ‘hard physical realities’ (Wendell 1996: 45) of impairment, for disabled participants the materiality of the body and impairment was very important because it had significant impact upon the ability to engage in sexual encounters at all. Thus impairment was often shrouded in negativity. The lived and embodied realities of impairment – whether aspects related to function and thus how the impaired body *performed* (such as incontinence, pain, fatigue, and immobility) or aesthetics, to how the impaired body *looked* (for example, non-normative embodiment such as scarring, deformity and muscle-wastage) – impairment was

foremost in peoples' minds when it came to physical sexuality, pleasure and their sexual selves. However, as seen in chapter six, many participants devised strategies to deal with the bodily difficulties that impairment brought and used 'different positions and various sexual aids to facilitate sexual fulfilment' (Shuttleworth 2010: 3). This shows although impairment was problematic within the confines of conventional notions of what constitutes a 'sexual body', my participants' management and strategies ensured that their bodies were sites of sexual pleasure and enjoyment. Further to this, for some other participants (though very few), impairment offered a means of experiencing polymorphous pleasure (Wilkerson 2002: 51), illustrating that impairment *can* shift conventional notions of pleasure and sexual norms, and more importantly, that it can potentially be experienced by people with impaired bodies, in certain contexts, as extraordinary, productive and exciting.

However, the impaired body was also positioned in participants' stories as more than a 'biological' reality and 'taken-for-granted fixed corporeality' (Meekosha 1998: 175) and constituted a site of social and cultural meaning. For example, as shown in chapter four, participants related to their impaired bodies as a source of difficulty in (per)forming a sexual identity within the social world. In chapter five the impaired body was a significant factor within intimate relationships with partners, particularly with regard to power relationships and the impaired body as a site of both care and abuse. In chapter six, impairment was regarded by participants as a troublesome presence when talking about their sexual desires and practices; and in chapter seven, the impaired body was embedded within disabled men's motivations to purchase sex, and imbricated within their experiences of male sexual power. Thus, I propose that the lived experience of impairment, its meaning, and

‘impairment effects’ – ‘the direct effects of impairment which differentiate bodily functioning from that which is socially construed to be normal or usual’ (Thomas 2002: 20) – must be recognised within theorisations of disabled peoples’ sexual lives. In order to attempt to diffuse the theoretical tensions outlined in chapter two between critical realist requirements to ‘mark’ the gritty realities of impairment and postmodern and post-structuralist perspectives of the body which are argued to ‘write-out’ such realities (see Wendell 1996) (or least ‘reduce’ them to discourse), my data has shown the need for impairment to be considered very much in terms of its ‘hard physical realities’ (Wendell 1996: 45). However, at the same time, as this chapter has shown so far, impairment also needs to be treated as a ‘relational, constructed, and negotiable’ (Goodley and Tregaskis 2006: 638) – and gendered – construct.

It is here, then, that I (tentatively) reiterate my concerns about the applicability of post-modern and queer radical redefinitions of impairment (Smith and Sparkes 2002, 2003; Wilkerson 2002). Such idealist revisions of the impaired body, as I suggested in chapter two, can fail to give enough consideration to the dis/ableist systems through which disability and impairment are produced (and the psycho-emotional consequences of such systems). More importantly, however, such revisions remain largely alien to those who sit outside of the academy and radical politics. While many participants successfully managed and negotiated the often unpleasant bodily realities of impairment (although this comprised a significant form of work) and, for some others, impairment disturbed sexual bodily norms and served as a site of new and non-normative embodied sexual pleasures, their conceptualisations of impairment predominantly as a negative and inhibiting factor

within the formation of a sexual self and sexual life problematises such idealist constructions of the body. However, I am in no way naturalising impairment, nor ignorant to the fact that my participants' lived experiences of, and the meanings attached, to impairment as predominantly negative is evidence of the very *need* to interrogate and challenge ableist heteronormativity – especially in relation to the unreachable notions of 'compulsory able-bodiedness' and what constitutes the 'able' sexual body (McRuer 2006: 2). Rather, my original concerns of intellectualising disabled sexualities and the impaired body to the point where such theorisations lose sight with disabled peoples' own realities, (particularly with regards to economic, social and institutional conditions), still remains. This is largely due to the considerable disparity of meaning between the everyday and theoretical, and because critical transformatory perspectives of the impaired body only as revised (Smith and Sparkes 2002, 2003), reconstituted (Meekosha and Shuttleworth 2009: 60), and cyborg (Haraway 1991) privilege too far – in the context of the bodily – the emancipatory possibilities of the impaired body over the realities experienced by my participants.

Managing and Negotiating Sexual Life

The sexual stories within my research have shown that disabled participants carried out a variety of forms of work within multi-farious spaces in order to manage and negotiate their sexual and intimate lives. Thus, I have made visible 'the telling, hiding, keeping up, waiting, teaching, networking and negotiating' (Church et al 2007: 10) required of disabled people within the disability experience, which, while well documented within disabled peoples' public lives (for example, Church et al 2007; Wong 2000), is less considered within 'private' life, and especially sexual life.

However, analysis has shown that the *necessity* to carry out work cannot be separated from the oppressive and inherent inequalities of ableist culture, or the psycho-emotional consequences it had for many participants.

Disabled participants (men and women) regularly took on the roles of teacher, negotiator, manager, mediator, performer, educator, and resistor through a wide variety of strategies. Thus, my research has illustrated the 'complex invisible "work" performed by disabled people in every day/night life' (Church et al 2007: 1). It has also revealed the extent to which the forms of work required were embedded in participants' daily reality. This again highlights the need to privilege, value, and theorise the more 'mundane' and 'routine' (yet relational and embodied) aspects of the disability experience as much as the often intangible, incorporeal and transgressive potentialities and possibilities put forward by some of the more radical revisions of disability and impairment. As I have stated in previous chapters, utopic conceptualisations of sexual life 'where there are no dis/abled sexualities' (Rembis 2010: 56) problematically contextualise 'emancipation' as constituting 'a thorough deconstruction and dissolution of identity intersections' (Shuttleworth 2010: 15) and of normative systems in general. This is not only (currently) a distinctly unattainable goal that seemingly underestimates the oppressive forces of sexual normalcy, but it offers little analytical attention to the forms of management and negotiation that disabled people (or excluded others) can – and do, as my data has shown – exercise both *within* and *inside* of oppressive sexual systems.

Participants' labour was diverse and served a variety of purposes within the construction of the sexual self. For example, some types of work were routine within the context of the disabled experience; such as managing the non-disabled gaze

(Reeves 2002) and the bodily realities of impairment (see previous section), and carrying out the extensive emotional work involved as a receiver of care. Some types of work served to reinforce rather than challenge normative sexuality and dominant constructions of disability. For example, chapters four and seven showed that methods to negotiate asexual identities were often centred only on *becoming* sexual, and chapter two demonstrated the extent to which participants' work involved performing the stereotypical or 'correct' emotions and characteristics of the disabled identity (for example, passivity, submissiveness, and timidity) only for the benefit of ableist 'demanding publics' (Goodley 2010: 93). Other types of work carried out were 'unsuccessful' and thus had notable psycho-emotional consequences; for example, chapter four demonstrated that despite disabled participants' efforts to gain or uphold privacy, there were few successful negotiations for privacy of one's self or body in the face of paternalistic discourses. This frequently left disabled participants' sexual bodies exposed and their sexual expression inhibited, which instigated feelings of inappropriateness, embarrassment and shame.

Significantly, some participants' strategies and forms of work had substantial psycho-emotional consequences and constituted significant harm. For example, chapter two revealed the extensive survival and emotional work required to both endure violence and abuse and stay in unhappy and unfulfilling relationships for the sake being partnered. While I have conceptualised this particular form of work as constituting participants' resilience and strength rather than victimhood, one cannot argue that these are strategies which fostered momentous emotional and physical harm. These forms of work act as painfully explicit examples that psycho-emotional disablism can be at its most acute when carried out by known agents (Reeve 2002);

however, participants also reported being bullied, abused, manipulated, exploited, chastised, ridiculed, humiliated and shamed in various other intimate spaces. Furthermore, even where harm (by others) was 'unintentional' or 'well meaning' (for example, participants being told by families not to 'get their hopes up' about finding love), these interactions still impacted upon the self-esteem and self-love required within fulfilling sexual and intimate lives (Shakespeare et al 1996).

Thus, much of the work employed by participants was, for the most part, located within social or interpersonal interactions with [non-disabled] others; for example, work took place with partners, PAs, in-laws, peers, [non-disabled/disabled] friends, doctors and other health professionals, strangers, PAs/carers, teachers, parents, families, partners, sex workers, bullies, fellow activists, and prospective partners. Thus, forms of interaction – what happens between people – has shown to be as relevant as the role of discourse in the construction of the disabled sexual self. Disabled participants' experiences of sexual opportunities, identities and encounters, and their strategies to manage and negotiate sexual life were not only produced or reproduced within discourse, but emanated within and through their interpersonal interactions with others. It is within these 'meaning laden interactions' (Brickell 2006: 416) that sexual identities were formed and reformed, thus demonstrating the utility of symbolic interactionism to theorisations of disabled sexualities. Thus, in the context of work and labours, the efficacy of a micro-social approach, through which disabled peoples' sexual agency in relation to others in day to day interactions can become visible (see Weeks 1986), was an effective instrument through which to explore this aspect of the disability experience.

The discovery of such labours within disabled peoples' sexual and intimate lives – regardless of its outcome or efficacy – I argue, forcefully challenges the ableist constructions of the disabled sexual identity and subjectivity as passive, asexual and as lacking sexual agency (Siebers 2008). Rather, this finding constitutes evidence that disabled people can be active and resourceful within their sexual lives. Furthermore, much of the work carried out was highly skilled, intricate and complex, and, paradoxically, is highly valued within the Western labour markets from which they are predominantly excluded (Barnes 1992; Abberley 2002). However, throughout this thesis I have emphasised that it is crucial not to underestimate the sizeable extent to which this work is rooted in, and thus indicative of, the oppressive and inherent inequalities of ableist culture. Rather than overt transgressive resistance, much of participants' work and strategies were carried out through *necessity* – for example, to survive; to be loved; to be human; to be included; to *be* 'normal'; to be sexual; and to be valued – and thus is revealing of the psycho-emotional disablism, oppression, and performances that disabled participants endured in order to be part of the ableist life world.

Conclusion

In sum, despite not telling the story I originally thought I would tell, my research and its findings have contributed to existing empirical and theoretical knowledges of disabled peoples' sexual and intimate lives. Despite a relatively small sample, by enquiring into the multiple intimate spaces of disabled peoples' sexual subjectivities and relationships, and through utilising a methodology that championed and privileged disabled peoples' voices and stories, my research has provided an insight into disabled participants' concerns, experiences, fears, feelings,

pleasures, and desires. Thus, I have – as the Research Advisory Group considered crucial – stayed faithful to participants' lived and embodied realities. However, if this thesis has a conclusion, it's that there remains considerable work yet to be done in the sexual and intimate areas of disabled peoples' lives; as Plummer (2008: 21) states, 'telling stories is our clue to the different lives that people lead, what we need are more stories and more dialogues between them all'. Thus, more than anything, what I hope this thesis has shown is that disabled sexual politics, possibilities and potentialities can only be discovered through truly listening to disabled peoples' sexual stories.

Appendices

Appendix 1: Research Advisory Group Mail-shot

THE UNIVERSITY OF WARWICK

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

The Sexualities of Physically Disabled and Sensory Impaired People Research Advisory Group

- **Do you consider yourself to have a physical disability or sensory impairment?**
- **Would you like to take part in a friendly and unique Research Advisory Group made up of disabled people which aims to guide an innovative and exciting piece of doctoral research about disabled peoples' experiences of sex and relationships?**
- **Do you have an evening to spare on Monday 17th August 2009 from 7.00pm – 9.00pm? If so, please come along to an introductory session being held at the very accessible venue of Milton Keynes Centre for Integrated Living (MK CIL) and take part in this informative evening.**

Monday 17th August 2009 from 7.00pm – 9.00pm

MK CIL, 330 Saxon Gate West, Central Milton Keynes, MK9 2ES

Although the research itself is about sexuality and relationships, attending an advisory group session does not involve discussing anything personal about yourself, your sexuality or your relationships, because its primary aim is to focus on guiding the research process. Refreshments will be provided and all travel expenses will be paid.

If you have any questions and would like any further information on the research or wish to attend the Research Advisory Group introductory session, please contact me. Alternatively, if you have any particular needs/requirements in order to facilitate your attendance please do get in touch:

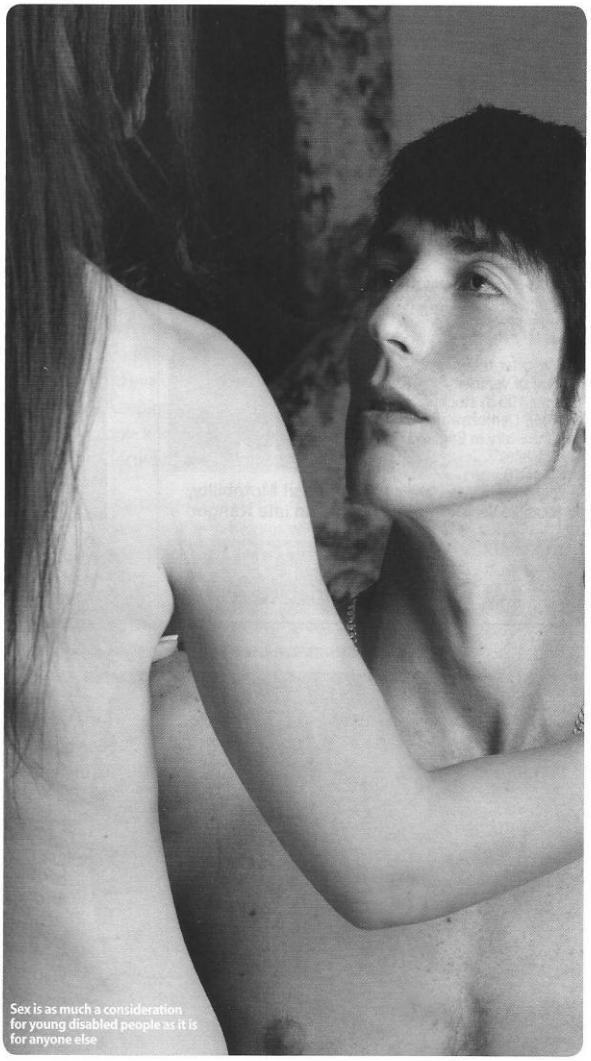
Kirsty Liddiard
k.liddiard@warwick.ac.uk
07970 583786

Appendix 2: Participant Recruitment: Target MD Article

The sex factor

Finding the confidence, opportunity and independence to begin a sexual relationship is a major issue for young people with a disability. **Jane Stein** discusses the barriers to fulfilling this normal part of life

Personal relationships and sex are an important part of life for most people. But sometimes it seems that society doesn't expect disabled people to have sex – and there might be a danger of this becoming a self-fulfilling prophecy. There is often a lack of awareness that young disabled people experience the same emotional and physical desires as their peers, and there may even be a belief that sex isn't possible for them. Actress Julie Fernandez (who appeared in the TV series *The Office*) has brittle bones and uses a wheelchair. She is also a prominent disability activist. In a piece for *The Guardian* (*Sex on Wheels*, 27 November 2007), she writes, "Even as a child I would be dreaming about husbands, sex and boyfriends, and I used to fantasise a lot."



Sex is as much a consideration for young disabled people as it is for anyone else

Parents vs personal life

Muscular dystrophy and many of the related neuromuscular conditions can cause increasing physical disability, meaning greater reliance on others for personal care as you go through your teenage years and enter adulthood. For young people who want to be independent and to develop friendships and relationships away from their parents, this can be a particularly tough time.

Parents may avoid discussing sex, believing it is kinder to their child not to raise their expectations. This is a false premise. At a neuromuscular symposium in Denmark in 2006, Evald Krog (President of the Danish Muscular Dystrophy Association), who has spinal muscular atrophy, gave an inspiring speech about the adult life of someone with a neuromuscular condition. He talked about how his parents "did not for a second doubt that my life should be like everybody else's life, including girlfriends, a wife and possibly children. Nevertheless… some things are more difficult when you have a severe physical disability… Like all teenagers, I desperately wanted to have a girlfriend. I wanted to have sex. I wanted to be confirmed in my belief that I had something to offer. And it took years before I succeeded. However, my father kept encouraging me. 'Try

Photos: iStock

again! Have you realised how many girls there are in Denmark?"'

Gaining sexual independence

Kirsty Liddiard, who is 25 and has a congenital muscular dystrophy, is a sociologist currently researching disabled people's experiences of sex and relationships. Her research is in the early stages, but from data collected so far she has found that disabled young people tend to gain experience of social and other relationships later than their non-disabled peers. This often leads to feelings of isolation and depression. It is difficult for severely disabled young people to keep social activities private from their parents when they are dependent upon them for personal care support. One young woman with limb-girdle muscular dystrophy said her parents struggled with the idea of her having sex. Many parents feel this way, but the parents of disabled young people are often more closely involved in their child's life, making it harder for the young person to have personal space and privacy. Young people also want – and need – some discussions they share only with their friends.

Maintaining a social life and meeting new people can be difficult, as Kirsty's research shows. Participants reported that nightclubs are a real challenge, as they tend to be particularly inaccessible and present lots of practical difficulties, such as how to buy a drink and carry it across a crowded area. Often, the carer of a young person is a parent (especially common if a young person is living at home) and in a nightclub this obviously creates a barrier when chatting to peers. It might help to think about arranging care support from someone outside the family. Try to rope in your mates – one tip is to ask your friends each to take responsibility for assisting you with a particular task (getting to the venue, buying drinks, accessing toilet facilities, etc). Remember, too, that despite what your mates may imply, not everyone is in a relationship or having sex.

Emotional barriers

Another problem identified by Kirsty's preliminary findings is a lack of self-love and self-esteem, and poor body-confidence. Society tends to emphasise the need for young men to display strength and power and for young women to look feminine. This presents problems for people with a wide range of disabilities. For example, many young women with Charcot-Marie-Tooth disease will express regret at being unable to wear high heels. The unrealistic media portrayal of the body beautiful doesn't help. Kirsty found that young disabled people feared rejection and humiliation, but that as people got older these worries became easier to speak about and share.

In her article for *The Guardian*, Julie Fernandez describes her experiences at a specialist boarding school, and talks about the practical and emotional challenges she has faced in her sexual relationships. "Over the period of getting to know someone, they would get to know what I was capable of," writes Julie. "Then the barriers would break down and they would realise that sex with a wheelchair-user is not so much of an issue. It always had to be that way round and I don't think I lost out by it."

Medical support

There tends to be a lack of dialogue from the medical profession. There is little specific information on how to cope when you have

"I want a relationship where I am valued"

Nick Wallis, who has Duchenne muscular dystrophy, has raised awareness of the difficulties facing disabled young people who want a sexual relationship

MANY PEOPLE WILL remember reading about Nick Wallis, a young man in his twenties with Duchenne muscular dystrophy who wanted to experience sex. Nick wrote an article for *The Guardian* (*First person*, 15 January 2007) and also talked about his wishes in a TV programme looking at the work of Helen and Douglas House hospices in Oxford. "Sex is one of the more difficult social aspects of disability," says Nick. "I speak from experience, having made the difficult decision to pay a sex worker. Of course this took much consideration and necessitated taking into account the feelings of other people, most particularly in my family. Speaking to your parents about sex is difficult enough for most young people. Although my experience was quite positive, what I seek is a 'proper' relationship in which I am valued as a person."

In his article for *The Guardian*, Nick wrote, "University is where many young people make their first serious forays into the world of relationships and sex. For the most part my attempts to form friendships or even to strike up a conversation were rebuffed. I felt like a foreigner in a new country, speaking a language no one understood." Nick wrote of his experience with the sex worker. "I am pleased that I had the tenacity and commitment to see it through. The experience, while not emotionally fulfilling, gave me confidence and a sense that I was not missing out. I regret that I couldn't be like everyone else and share a first sexual relationship with someone I knew and loved, and part of me feels that having to resort to paying a woman for sex reflects something lacking in society, not least because I know that some people disapproved of my actions." His openness generated much-needed debate. One individual wrote on the *Mail Online* message board: "I think Nick Wallis has done a great service to other disabled people who might, until now, have been too scared to make the same request. Good for you, Nick!"

"Parents often avoid discussing sex, believing that it's kinder to their child not to raise their expectations. However, this is a false premise"

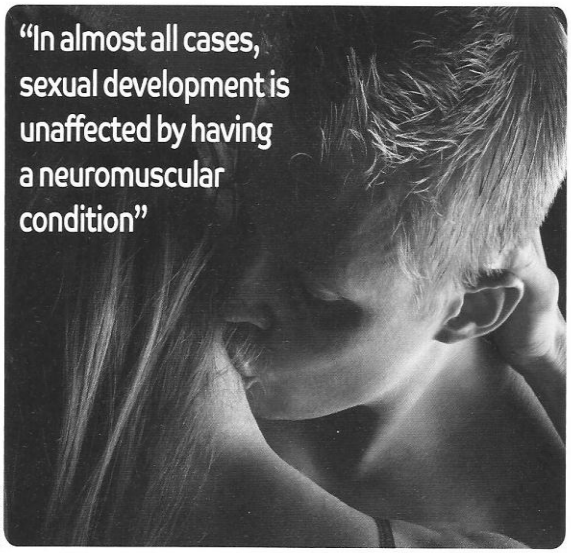


Photo: iStock

limited movement or have contractures. Young people should be encouraged to see medical staff without their parents/care worker in the room so that such discussions can be had in private. Doctors are obliged to respect confidentiality and will not share information with the parents of people over the age of 16 if they are asked not to. They will disclose information given by under 16-year-olds only if they believe there is a good reason to do so.

Some young people (for example, those with congenital or childhood onset myotonic dystrophy) may have learning difficulties. All young people need information about how their body works and how they develop physically, emotionally and sexually, therefore young people with learning difficulties must also always be included in discussions. Awareness about the vulnerability of people with learning disabilities is important, as is discussing with them the setting of personal boundaries. For example, how to say 'no' if you don't want someone to touch you, or who you can talk to if something just 'feels wrong'. *You, Your Body and Sex,* the DVD mentioned at the end of this article, may be helpful here.

In almost all cases, sexual development is unaffected by having a neuromuscular condition and even people very severely disabled by their condition (for example, as some with Duchenne muscular dystrophy may be) are able to have sex. It is important to remember that sex is a very personal thing – only do what makes you, and any partner you may be with, happy and comfortable. Certain positions may be easier – experiment to see what suits you.

***Note**: If you are the parent of a young person with a neuromuscular condition, please pass this article on to them!*

Let's talk about sex and relationships

Kirsty Liddiard is currently doing her doctoral research on disabled peoples' experiences of sexuality and relationships at the University of Warwick, and is looking for disabled men and women of any age, sexual orientation or ethnicity who are willing to take part.

The research is looking at many aspects of sex and relationships, such as finding a partner, relationships, sex, care, adolescence and body image. There are different ways you can share your experiences. For example, you can take part in a relaxed and conversational interview, either face-to-face or via instant messaging (such as MSN), email or telephone. Alternatively, you can write your thoughts and experiences down in the form of a journal.

If you have any questions and would like further information on the research, or would like to take part, please contact Kirsty.
Email: **k.liddiard@warwick.ac.uk**
Telephone: **07970 583786**

Resources

The Muscular Dystrophy Campaign cannot recommend other organisations or services, but the following listings are provided for your information:

- **Outsiders** An organisation run by disabled people for disabled people, open to all aged 16 and over. The website contains a huge amount of information about sex and relationships (much of it very explicit) and publishes leaflets including *Physical Disability and Sexual Intercourse.* Call **020 7354 8291** or visit **www.outsiders.org.uk**
- **Brook** Provides information about sexual health and relationships to people under 25 and has a network of local centres. Call **020 7284 6040** or visit **www.brook.org.uk** for details. Their helpline is **0800 018 5023**.
- **Family Planning Association** Gives advice and publishes useful guides on a range of issues connected with growing up. Their helpline number is **0845 310 1334** or you can visit **www.fpa.org.uk**
- **Contact a Family** Publishes three useful booklets (one each for young people, parents and teachers) on growing up, sex and relationships. Call **0808 808 3555** or you can visit **www.cafamily.org.uk**
- **You, Your Body and Sex** This DVD may be useful for young people with learning difficulties. From Life Support Productions. ISBN 0-9551735-2-3.
- **TLC Trust** helps professional sex workers cater for the needs of disabled people **www.tlc-trust.org.uk**
- **Leonard Cheshire Disability** This charity is running a three-year project looking at resources giving disabled 14 to 25 year olds greater access to sexual health information and services **www.lcdisability.org/intouch**
- **YouTube** features lots of discussion around sex and relationships **www.youtube.com**

*Contact us

If you have a story you would like to share with others contact our Director of Care & Support

Lyn Inman
020 7803 4802
lyni@muscular-dystrophy.org

Doctorate research into sex

A research study into the relationships of deaf and hard of hearing people will promote understanding of sensory impairments in society

Kirsty Liddiard is a sociologist conducting doctoral research on disabled and sensory impaired peoples' experiences of sexuality and relationships at the University of Warwick.

"Common assumptions of the sex lives and relationships of people with disabilities or sensory impairments are predominantly negative and incorrect within society," said Kirsty. "As a result such relationships are either denied through being considered as 'non-existent', or defined as 'inadequate' or 'immoral'."

"It is this distinct inequality that the research aims to challenge. The study is sociological, meaning that the findings will contribute to our understanding of the ways in which people with

physical and sensory impairments manage and negotiate their sex lives and relationships in spite of society's assumptions."

Kirsty is currently looking for people who are deaf or hearing impaired to take part in the research, which will look at aspects of sex and relationships including finding a partner, adolescence and body image.

There are several ways individuals can share their experiences by taking part in a relaxed and conversational interview: face to face (with or without a BSL interpreter); via text phone; through instant messaging or email.

For further information and to take part in the research, contact:
Kirsty Liddiard
Department of Sociology
University of Warwick
Coventry, CV4 7AL
Direct Line: 07970 583786
Email: k.liddiard@warwick.ac.uk
Web: www2.warwick.ac.uk/study/cde/gsp/eportfolio/directory/pg/sypgbj/

watching a film (where you could doze off perhaps). A boat ride where you just relax and watch the view could also be an option. I am sure you could come up with ideas of your own, you just need the confidence to say how things are, and assertiveness to insist on your needs and boundaries.

Dear Tuppy

I have I have rheumatoid arthritis and realise I will soon have to stop work. I dread sitting alone at home all day, I will miss my work mates and meeting new people.
I know you can't work miracles, but can you lift my spirits?

Doomed

Dear Doomed.

You may be able to continue working, supported by the government's Access to Work programme. This provides funding for equipment and other means of overcoming barriers that exclude people from work. Such support and funding is due to you, under the Disability Discrimination Act 1995.

Not knowing what your job is, there may be other jobs that you can do instead? There is always voluntary work (for Outsiders, for example). There is no need for anybody to sit alone doing nothing. If you stop earning money, you'll receive benefits which will mean you can go out and about enjoying friendships and having fun.

Important Research Project Seeks Your Help

Kirsty Liddiard is doing her doctoral research on disabled peoples' experiences of sexuality and relationships.

This is a great opportunity to make your views and needs known in a way that will influence the way disabled people are treated in the future. We in Outsiders have realised that however much we talk about these things and discuss them in INSIDE, the powers that be won't take any notice unless the evidence is presented in academic research.

Kirsty is looking for men and women of any sexual orientation/ age/ethnicity and with physical, sensory and social disabilities, who would like to take part in a relaxed and conversational interview, or who would like to keep a journal for a certain period of time (decided by you) about aspects of sexuality such as relationships, sex, care, childhood, adolescence, and partners. The interview can be through email, instant messaging (e.g. MSN) or in person at a location of your choice (e.g. your home) and may last up to 2 hours. The journal can be viewed as a more private or convenient way of sharing your thoughts, or a more creative project through which you can write your

'story' and with which you would have more involvement. It will cover the same topics as the interview and can be written/typed or spoken; the format is completely up to you.

Confidentiality and anonymity will be upheld at all times and all expenses will be paid.

Kirsty is also looking for people who would like to contribute to one or more Research Advisory Group sessions deciding on the research process. This group is a very important aspect of the research because much academic research on disability is conducted and controlled by those who do not have a disability. As a result, academic research is often only published in academic and governmental contexts, and is criticised by disabled people as not representing their true voice.
You can attend as many or as few sessions of the group as you wish. It is thought that around 5 sessions will be held over the following year. Alternatively, if you don't want to take part in any of the group sessions, you can contribute your thoughts on the research process via telephone or email.
Unfortunately due to funding restrictions travel expenses can only be reimbursed for those who live within Buckinghamshire.

Contact: Kirsty Liddiard
Doctoral Researcher,
Dept. of Sociology, University of Warwick, Coventry CV4 7AL.
Email: k.liddiard@warwick.ac.uk
Direct Line: 07970 583786

THE MANDI PEERS COLUMN

How to Go Out – a 2-step guide

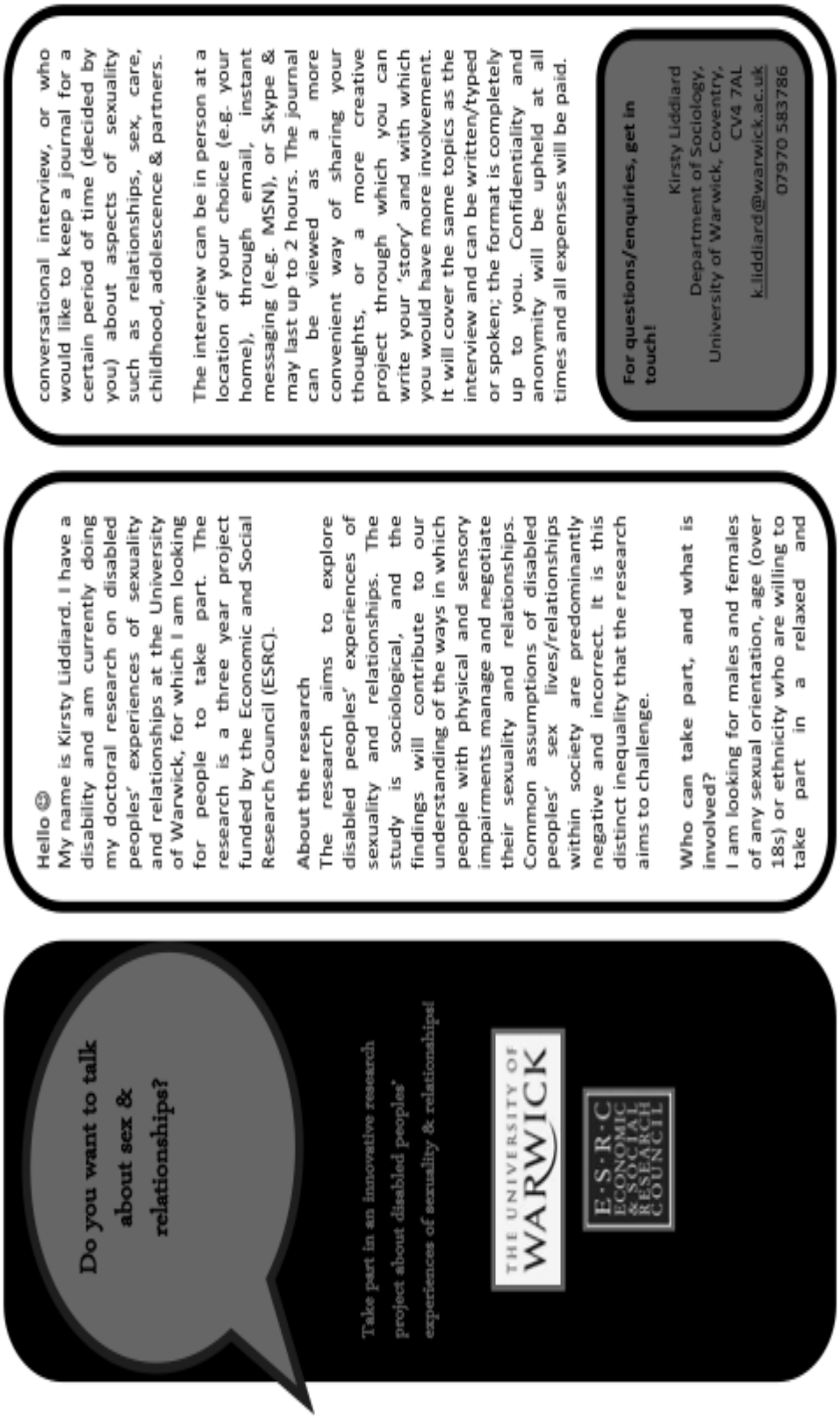
This might seem a strange topic, as everyone knows how to go out and party — don't they? However, a lot of disabled people struggle with going out and socialising for many reasons: lack of accessible venues, health problems, and not least, the cost of it!

Even those of us who don't need to take a PA may still have to use taxis rather than public transport, all of which hikes up the cost even before we've paid to get in. Fortunately a lot of places increasingly give concessions for disabled people, such as two for the price of one admission, so you can afford to bring a companion.

Here it is, the 2-step guide on How to Go Out. If you don't need any advice, skip this bit and go straight to the venue listings.

Find the party! Most venue websites give listings of their upcoming events. You could also try the following general music sites: www.seetickets.com www.time-out.com
www.giglistings.co.uk, or
www.raveguide.co.uk,
www.accessallareas.org, and many

Appendix 5: Participant Recruitment: Young Persons' Respite Care Hospice Leaflet



Do you want to talk about sex & relationships?

Take part in an innovative research project about disabled peoples' experiences of sexuality & relationships!

THE UNIVERSITY OF WARWICK

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Hello ☺
My name is Kirsty Liddiard. I have a disability and am currently doing my doctoral research on disabled peoples' experiences of sexuality and relationships at the University of Warwick, for which I am looking for people to take part. The research is a three year project funded by the Economic and Social Research Council (ESRC).

About the research
The research aims to explore disabled peoples' experiences of sexuality and relationships. The study is sociological, and the findings will contribute to our understanding of the ways in which people with physical and sensory impairments manage and negotiate their sexuality and relationships. Common assumptions of disabled peoples' sex lives/relationships within society are predominantly negative and incorrect. It is this distinct inequality that the research aims to challenge.

Who can take part, and what is involved?
I am looking for males and females of any sexual orientation, age (over 18s) or ethnicity who are willing to take part in a relaxed and conversational interview, or who would like to keep a journal for a certain period of time (decided by you) about aspects of sexuality such as relationships, sex, care, childhood, adolescence & partners.

The interview can be in person at a location of your choice (e.g. your home), through email, instant messaging (e.g. MSN), or Skype & may last up to 2 hours. The journal can be viewed as a more convenient way of sharing your thoughts, or a more creative project through which you can write your 'story' and with which you would have more involvement. It will cover the same topics as the interview and can be written/typed or spoken; the format is completely up to you. Confidentiality and anonymity will be upheld at all times and all expenses will be paid.

For questions/enquiries, get in touch!
Kirsty Liddiard
Department of Sociology,
University of Warwick, Coventry,
CV4 7AL
k.liddiard@warwick.ac.uk
07970 583786

Appendix 6: Introductory Sheet

Doctoral Research Study: The sexualities of physically disabled and sensory impaired people

About me

My name is Kirsty Liddiard. I am currently doing my doctoral research on disabled peoples' experiences of sexuality and relationships at the University of Warwick, for which I am looking for people to take part. The research is a three year project funded by the Economic and Social Research Council (ESRC). I also have a disability myself, called Congenital Muscular Dystrophy.

About the research

The research aims to explore disabled peoples' experiences of sexuality and relationships. The study is sociological, and the findings will contribute to our understanding of the ways in which people with physical and sensory impairments manage and negotiate their sexuality and relationships. Common assumptions of disabled peoples' sex lives/relationships within society are predominantly negative and incorrect and thus those relationships are either denied through being considered as 'non-existent', or problematised through being defined as 'inadequate' or 'immoral'. It is this distinct inequality that the research aims to challenge.

Who can take part, and what is involved?

I am looking for men and women (of any sexual orientation/age/ethnicity) who are willing to take part in a relaxed and conversational interview, or who would like to keep a journal for a certain period of time (decided by you) about aspects of sexuality, for example, relationships, sex, care, childhood, and adolescence. The interview can be through email, instant messaging (e.g. MSN) or in person at a location of your choice (e.g. your home) and may last up to 2 hours. The journal can be viewed as a more private or convenient way

of sharing your thoughts, or a more creative project through which you can write your 'story' and with which you would have more involvement. It will cover the same topics as the interview and can be written/typed or spoken; the format is completely up to you.

The very nature of the research means the content can be intimate and personal. However, how much and what you discuss will be very much up to you and you can end your participation at any time. Confidentiality and anonymity will be upheld at all times and all expenses will be paid.

What if I don't want to take part, but still want to be involved?

If you don't feel you can take part in the research itself but would still like to be involved, I am also looking for people who would want to contribute to one or more **Research Advisory Group** sessions regarding many aspects of the research process.

The group is a very important aspect of the research because much academic research on disability is conducted and controlled by those who do not have a disability. As a result, academic research is often only published in academic and governmental contexts, is criticised by disabled people as not representing their true voice and overall becomes that which fails to transfer to the reality of disabled people's lives. My research methodology aims to challenge this and therefore it is vital that the research be guided by disabled people themselves to ensure that it is inclusive, accessible and representative. Although the research itself is about sexuality and relationships, attending an advisory group session **does not** involve discussing anything personal about yourself, your sexuality or your relationships because its primary aim is to focus on guiding the research process.

You can attend as many or as few sessions of the group as you wish. It is thought around 5 sessions will be held over the following year, please contact me for details of the next one. **All are welcome, but unfortunately due to funding restrictions travel expenses can only be reimbursed for those who live within Buckinghamshire.** Alternatively,

if you don't want to take part in any of the group sessions, you can contribute your thoughts on the research process via telephone or email.

If you have any questions and would like any further information on the research, or would like to take part, don't hesitate to contact me.

Kirsty Liddiard, Doctoral Researcher,
Dept. Of Sociology,
University of Warwick, Coventry, CV4 7AL
Email: k.liddiard@warwick.ac.uk Direct Line: 07970 583786

Appendix 7: Participant Information Sheet

Participant Information Sheet

What is the purpose of the study?

The overall purpose of the study is to understand disabled people's experiences of their sexuality and relationships. More specifically, I am looking at:

- How disabled people understand the immediate life world shapes their sexual opportunities and identities.
- The strategies disabled people employ in order to manage and negotiate their sexuality and whether such strategies change over time.
- The ways that disabled people narrate and present their sexual stories and experiences.

Why have I been invited?

You have been invited to participate because your experiences will add further breadth and depth to the data collected. I am planning to gather the experiences of around 30-40 people from a wide range of different disabilities, backgrounds, genders, sexualities and ethnicities over the following year.

Do I have to take part?

No, it is up to you to decide. This information sheet describes what is involved and you are free to ask any questions before you decide. If you do choose to take part, you are free to withdraw at any time. This includes any data you may have given up until the point of withdrawing.

What will happen if I take part?

If you decide to take part, it is up to you to choose the way to would like to offer your own experiences of sexuality, sex and relationships, or what I will call your ‘sexual story/ies or narratives’. The choices are **either**:

1) An interview, which can take place in a format to suit you. For example, the interview can take place in person at a location convenient to you (e.g. your home), or alternatively can take place through an exchange of emails, via telephone or through online instant messaging. The interview may take up to two hours, although this can be broken up into more than one session if preferred. The interview will be recorded and transcribed for analysis.

2) To offer your experiences through writing a journal of your ‘sexual stories’. Again, this can be carried out in a format that suits you. For example, instead of writing your journal, you can 'speak' it instead, similar to a 'spoken-word' diary using a tape recorder or Dictaphone which can be

provided.

What if I don't want to share my personal experiences, but still want to take part in the research?

The research process will be guided by advisory group sessions made up of disabled people which will take place at an accessible location in the Milton Keynes area. The aims of the sessions are to facilitate disabled people themselves to guide the research process, making it (where possible) user-led. A lot of disability research is carried out with little input from disabled people making it inaccessible and disempowering; as a result, quite often the findings fail to transfer to the reality of disabled people's lives. In contrast this research project seeks feedback and guidance from disabled people at various stages of the research process which will be obtained through discussion within advisory group sessions.

If you do not feel you want to talk about your own experiences, but still would like to be involved in the research, attending one or more advisory group sessions could be for you. The advisory group sessions do not involve you revealing anything intimate about yourself or your relationships, and your input would be related to the research process only.

Alternatively, if you wish, you can both take part in a advisory group session and take part in the research through completing a journal or being interviewed

If you wish to discuss any of the above with me, or would like help working out which method may be best for you, please don't hesitate to contact me. After you have decided which method and format you would like to offer your story in, simply let me know and I can set this up for you.

Will all of my information be kept confidential?

Yes. All identifying information and audio-recordings will be kept securely. All identifying information will be removed from the transcripts, and in any subsequent publications and presentations on the findings of the study, all information will be changed. At the end of the study, the audio-recordings will be destroyed and the anonymised scripts will be retained by me.

What are the possible disadvantages and risks of taking part?

It is possible that speaking about your experiences of sexuality, sex and/or relationships may touch upon issues that you may find upsetting or which you would prefer not to discuss. In this case, you do not have to answer particular questions, and can end the session at any time. If you do feel you need to discuss things further after taking part, a post-research counselling session may be set up free of charge with a counsellor who knows about the research.

In addition, while every possible step will be taken to ensure confidentiality, there is still a possibility that you might be recognisable in the findings to people who know you well - for example a family member or friend. In particular, the research write-

up will contain (anonymised) word-for-word quotations from interviews or journals, which carry a light risk of making the speaker recognisable. I will make every effort to avoid this possibility by changing all names and other key pieces of identifying information.

What are the possible benefits of taking part?

Some people may find talking about such issues in an open environment liberating and find that it helps them. I cannot promise that taking part in the study will help you, but the information I get from the study will help to improve understanding of some of the issues surrounding sexuality and relationships for disabled people.

Taking part in the advisory group offers an opportunity to give your thoughts on the research and how it is being carried out, thus having a valuable input into an exciting and innovative piece of research.

Where will the research be published?

It is hoped that the research, or parts of it, will be published within academic journals and chapters of academic books. In addition, in order to make sure the research and its findings are accessible to the public, findings from research will go into articles which may be published in disability lifestyle magazines (e.g. Disability Now, Able) as well as more mainstream publications. The research and its findings will also be used as part of papers/presentations given at academic, practitioner, and service user conferences/events.

As stated earlier, all data will be anonymised and where direct quotations are used I will make every effort to change all names and other key pieces of identifying information. This will ensure that in any subsequent publications and presentations on the findings of the study, all information will be changed.

What if there was a problem?

If you have a concern about any aspect of the research, do get in touch with me and I'll do my best to answer any questions. As stated previously, if you are unhappy with anything during the research you have the right to withdraw at any time; this includes the withdrawal of any data already collected.

Further information and contact details

If you have any further questions about the study at any point, please do not hesitate to contact me. My contact details are as follows:

Kirsty Liddiard
PhD Researcher
Department of Sociology
University of Warwick
Coventry
CV4 7AL

Tel: 07970 583786
Email: k.liddiard@warwick.ac.uk

Supervisors

Dr Karen Throsby
Department of Sociology
University of Warwick
Coventry
CV4 7AL

Tel: 02476 575129
Email: K.throsby@warwick.ac.uk

Dr Carol Wolkowitz
Department of Sociology
University of Warwick
Coventry
CV4 7AL

Tel: 02476 523159
C.wolkowitz@warwick.ac.uk

Appendix 8: Consent Form

Doctoral Research Study: The sexualities of physically disabled and sensory impaired people

Consent Form

I freely and voluntarily consent to be a participant in the research project on the topic of disability and sexuality to be conducted by Kirsty Liddiard as principle researcher, who is a postgraduate student in the Department of Sociology at the University of Warwick. The broad goal of this research study is to explore disabled peoples' experiences of sexuality and relationships.

I have read and understood the Participant Information sheet which details the research process and my rights as a participant. I have been told that my responses will be kept strictly confidential. I also understand that if at any time during the interview or journal writing process I feel unable or unwilling to continue, I am free to leave. That is, my participation in this study is completely voluntary, and I may withdraw from it at any time without negative consequences. [In addition, should I not wish to answer any particular question or questions, I am free to decline.] All data I have already provided will be withdrawn should I withdraw from the research. My name will not be linked with the research materials, and I will not be identified or identifiable in any report subsequently produced by the researcher.

I have been given the opportunity to ask questions regarding the research process, and my questions have been answered to my satisfaction. I have been informed that if I have any general questions about this project, I should feel free to contact Kirsty Liddiard (see contact details below). If I have any comments or concerns about the ethics procedures employed in this study, I can Kirsty Liddiard's supervisers; Dr Karen Throsby and/or Dr Carol Wolkowitz (see contact details below).

I have read and understand the above and consent to participate in this study. My signature is not a waiver of any legal rights. Furthermore, I understand that I will be able to keep a copy of the informed consent form for my records.

_____

Participant's Signature Date

Further information and contact details

If you have any further questions about the study at any point, please do not hesitate to contact me. My contact details are as follows:

Kirsty Liddiard
PhD Researcher
Department of Sociology
University of Warwick
Coventry
CV4 7AL
Tel: 07970 583786
Email: k.liddiard@warwick.ac.uk

Supervisors

Dr Karen Throsby
Department of Sociology
University of Warwick
Coventry
CV4 7AL
Tel: 02476 575129
K.throsby@warwick.ac.uk

Dr Carol Wolkowitz
Department of Sociology
University of Warwick
Coventry
CV4 7AL
Tel: 02476 523159
C.wolkowitz@warwick.ac.uk

Appendix 9: Participant Demographic Questionnaire

Initial Questionnaire (prior to interview/journal)

General Information

Gender _____

Age _____

Type of education

Mainstream

Special

Both **(please explain _____)**

Educational Level	**Parent's Educational Level**
GSCE	GSCE
A Level/College	A Level/College
University (undergraduate)	University (undergraduate)
University (Higher)	University (Higher)

Accommodation/living	**Who do you live with?**
Council	Alone
renting	Friends
Private renting	Partner
Own home	Family/Parents

Sexual Orientation

Homosexual	Bisexual
Heterosexual	Other

Employment Voluntary work

Employed Unemployed

Ethnicity _____

Disability

What is your disability/impairment? _____

Is your disability/impairment Congenital (from birth)

Acquired Age of onset ____

Appendix 10: Original Interview Schedule

Interview Schedule – First draft

- **Research Questions**
- How do physically disabled and sensory impaired adults understand the immediate life world shapes their sexual opportunities and identities?
- What strategies do physically disabled and sensory impaired adults employ in order to manage and negotiate their sexuality and how do these strategies change over time?
- How do physically disabled and sensory impaired adults narrate their sexual stories and present their experiences?

Body/identity/imagery

How do you feel your disability/impairment affects your self-confidence/esteem?

How do you feel your disability/impairment affects your sense of self?

Do you feel attractive or sexy?

Do you compare your body/image to the cultural ideal of masc/fem? (e.g. pics in mags/media) How does this make you feel?

Do you consider your disability/impairment as part of your identity? Why?

Childhood (taken from Gillespie-Sells, K., Hill, M., Robbins, B. (1996) *She Dances to Different Drums: Research into Disabled Women's Sexuality.* London: King's Fund)

As a child, did you have any ideas about relationships?

As a child, did you expect to marry and have children?

Do you think your parents/teachers had expectations of you having relationships/getting married?

Puberty

Tell me about your experiences of puberty.

How did you feel about your changing body during puberty?

How did others react to you the changes you were going through?

At what age did you begin having sexual feelings?

Did you have any relationships/sex during teenage years? (When, why, how was that experience?)

How did you find social life as a teenager?

When and where did you learn about sex/contraception etc? How did it make you feel?

How do you feel your experiences of adolescence compared to that of a non-disabled person?

Relationships

Can you tell me about previous relationships you've had?

Are you currently in a relationship or have a sexual partner? Yes/No

Can you tell me a little bit about your partner and the history of this relationship?

What did/do you enjoy about your relationship/s?

What did/do you fear in your relationship/s?

Did/do you consider your disability to be a factor within this relationship/s? If so, how?

How do you think others feel /felt about you having a non-disabled/disabled partner?

Caring and support (within a relationship)

Is/was physical care a part of your relationship/s?

How did/do you think caring affects your relationship/s?

How did/does being cared for by your partner/s make you feel?

How does caring affect your role within the relationship/s?

How does the presence of caring affect the sexual aspects of your relationship/s?

Do/have you care/d for your partner?

Not currently with a partner

Would you like to be in a relationship?

Are you looking for a partner/sex? How?

What other methods have you used to meet prospective partners?

How do you think others view you're being single?

Never had a relationship/sex

Would you like to have sexual/relationship partners?

Why do you think you have not experienced a relationship/partner?

Do you consider there to be difficulties in finding a partner? If so, do you have any way around these?

Have you used the internet? Can you tell me about these experiences?

What would you look for in a prospective partner/relationship? (Inc. disabled or non-disabled)...

Have you ever considered paying for sex?

Sex

Disability and sex

Do you consider your disability/impairment to influence your enjoyment of sex?

Are there any physical reasons resulting from your impairment that influence your enjoyment of sex? (inc catheters/colostomies)

Do you consider your disability/impairment to influence the role you play in sex?

Are you on any medication that affects sexual function? How does this make you feel?

Are there any particular aspects of sex you enjoy (...)?

Are there any particular aspects of sex you don't enjoy? Why?

Do you use any toys/aids/assistance within sex?

If you do require assistance/facilitation during sex, who provides this, and is this arrangement satisfactory?

Do you use masturbation as part of your sex life?

Sex talk

Do you discuss sex with anyone (other than your partner if you have one)?

Have issues around sex ever been raised with GPs, consultants, OTs (either by you or them)?

Where would you get information on sex if you wanted it?

Do you join in with sex talk with non-disabled men/women?

Do you join in with sex talk with disabled men/women?

Other

Paid-for Care

Do you receive any professional care?

Do you have a regular care worker? How do you find this relationship?

How does a paid-for carer touching your body make you feel?

Appendix 11: Interview Schedule Amendment to Include a Partner, revised October 2009

Interview Schedule – For couples (DP (disabled person) and NDP (non-disabled person))

- **Research Questions**
- How do physically disabled and sensory impaired adults understand the immediate life world shapes their sexual opportunities and identities?
- What strategies do physically disabled and sensory impaired adults employ in order to manage and negotiate their sexuality and how do these strategies change over time?
- How do physically disabled and sensory impaired adults narrate their sexual stories and present their experiences?

Body/identity/imagery

How do you feel your disability/impairment affects your self-confidence/esteem? (DP)

How do you feel your disability/impairment affects your sense of self? (DP)

Do you feel attractive or sexy? (DP)

Do you consider your disability/impairment as part of your identity? Why? (DP)

Childhood (taken from Gillespie-Sells, K., Hill, M., Robbins, B. (1996) *She Dances to Different Drums: Research into Disabled Women's Sexuality.* London: King's Fund)

As a child, did you have any ideas about relationships?

As a child, did you expect to have a life partner? (DP)

As a child, did you expect to marry and have children? (DP)

Do you think your parents/teachers had expectations of you having relationships/getting married? (DP)

Puberty

Tell me about your experiences of puberty. (DP)

How did you feel about your changing body during puberty? (DP)

How did others react to you the changes you were going through? (DP)

At what age did you begin having sexual feelings? (DP)

Did you have any relationships/sex during teenage years? (When, why, how was that experience?) (DP)

How did you find social life as a teenager? (DP)

When and where did you learn about sex/contraception etc? How did it make you feel? (DP)

How do you feel your experiences of adolescence compared to that of a non-disabled person? (DP)

Relationships

Can you tell me about previous relationships you've had? (DP)

Can you tell me a little bit about your partner and the history of this relationship? (DP & NDP)

What did/do you enjoy about your relationship/s? (DP & NDP)

What did/do you fear in your relationship/s? (DP & NDP)

Did/do you consider your disability to be a factor within this relationship/s? If so, how? (DP & NDP)

How do you think others feel /felt about you having a non-disabled/disabled partner? (DP & NDP)

Caring and support (within a relationship)

Is/was physical care a part of your relationship/s? (DP & NDP)

How did/do you think caring affects your relationship/s? (DP & NDP)

How did/does being cared for/caring for your partner/s make you feel? (DP & NDP)

How does caring affect your role within the relationship/s? (DP & NDP)

How does the presence of caring affect the sexual aspects of your relationship/s? (DP & NDP)

Do/have you care/d for your partner? (DP)

Pre- partner

What methods have you used to meet prospective partners/sex? (DP)

How did you think others viewed your being single? (DP)

Do you consider there to be difficulties in finding a partner? If so, do you have any way around these? (DP)

Have you used the internet? Can you tell me about these experiences? (DP)

Do you disclose your disability on the internet? If so, when? (DP)

Have you ever considered paying for sex? (DP)

Sex

Disability and sex

Do you consider your disability/your partner's disability influence your enjoyment of sex? (DP & NDP)

Are there any physical reasons resulting from your impairment that influence your enjoyment of sex? (inc catheters/colostomies) (DP)

Do you consider your disability/your partner's disability to influence the role you play in sex? (DP & NDP)

Are you on any medication that affects sexual function? How does this make you feel? (DP)

Are there any particular aspects of sex you enjoy (...)?(DP & NDP)

Are there any particular aspects of sex you don't enjoy? Why? (DP & NDP)

Do you use any toys/aids/assistance within sex? (DP & NDP)

If you do require assistance/facilitation during sex, who provides this, and is this arrangement satisfactory? (DP & NDP)

Do you use masturbation as part of your sex life? (DP & NDP)

Sex talk

Do you discuss sex with anyone (other than your partner if you have one)? (DP & NDP)

Have issues around sex ever been raised with GPs, consultants, OTs (either by you or them)? (DP)

Where would you get information on sex if you wanted it? (DP & NDP)

Do you join in with sex talk with non-disabled men/women? (DP)

Do you join in with sex talk with disabled men/women? (DP)

Other

Paid-for Care

Do you receive any professional care? (DP)

Do you have a regular care worker? How do you find this relationship? (DP)

How does a paid-for carer touching your body make you feel? (DP)

Appendix 12: Interview Schedule, revised March 2010

Interview Schedule Revised

- **Research Questions**
- How do physically disabled and sensory impaired adults understand the immediate life world shapes their sexual opportunities and identities?
- What strategies do physically disabled and sensory impaired adults employ in order to manage and negotiate their sexuality and how do these strategies change over time?
- How do physically disabled and sensory impaired adults narrate their sexual stories and present their experiences?

Body/identity/imagery

How do you feel your disability/impairment affects your self-confidence/esteem?

How do you feel your disability/impairment affects your sense of self?

Do you feel attractive or sexy? When are these times?

Do you compare your body/image to the cultural ideal of masc/fem? (e.g. pics in mags/media) How does this make you feel?

Do you consider your disability/impairment as part of your identity? Why?

Childhood (taken from Gillespie-Sells, K., Hill, M., Robbins, B. (1996) *She Dances to Different Drums: Research into Disabled Women's Sexuality.* London: King's Fund)

As a child, did you have any ideas about relationships?

As a child, did you expect to marry and have children?

Do you think your parents/teachers had expectations of you having relationships/getting married?

Puberty

Tell me about your experiences of puberty.

How did you feel about your changing body during puberty?

How did others react to you the changes you were going through?

At what age did you begin having sexual feelings?

Did you have any relationships/sex during teenage years? (When, why, how was that experience?)

How did you find social life as a teenager?

When and where did you learn about sex/contraception etc? How did it make you feel?

How do you feel your experiences of adolescence compared to that of a non-disabled person?

University

How did things change when you went to university?

Did you experience any sex or relationships at university?

What was social life like at university?

Relationships

Can you tell me about previous relationships you've had?

Are you currently in a relationship or have a sexual partner? Yes/No

Can you tell me a little bit about your partner and the history of this relationship?

What did/do you enjoy about your relationship/s?

What did/do you fear in your relationship/s?

Did/do you consider your disability to be a factor within this relationship/s? If so, how?

How do you think others feel /felt about you having a non-disabled/disabled partner?

Care/PAs

Do you receive any professional care?

Do you have a regular care worker? How do you find this relationship?

How does a paid-for carer touching your body make you feel?

Caring and support (within a relationship)

Is/was physical care a part of your relationship/s?

How did/do you think caring affects your relationship/s?

How did/does being cared for by your partner/s make you feel?

How does caring affect your role within the relationship/s?

How does the presence of caring affect the sexual aspects of your relationship/s?

Do/have you care/d for your partner?

Not currently with a partner

Would you like to be in a relationship?

Are you looking for a partner/sex? How?

What other methods have you used to meet prospective partners?

How do you think others view you're being single?

Never had a relationship/sex

Would you like to have sexual/relationship partners?

Why do you think you have not experienced a relationship/partner?

Do you consider there to be difficulties in finding a partner? If so, do you have any way around these?

Have you used the internet? Can you tell me about these experiences?

What would you look for in a prospective partner/relationship? (Inc. disabled or non-disabled)...

Have you ever considered paying for sex? YES/NO (If yes, see section below)

Sex workers

How many times have you seen a sex worker? When/how often/where

Can you tell me what led up to making the decision to use one initially? What was it like the first time?

If once, would you do it again? Why?

Can you tell me about some of your experiences with sex workers?

What are the pros and cons of using sex workers?

What does it feel like to pay for sex?

Does it give you what you seek/want?

Where do you locate them? E.g. internet/agency/street

Have you ever experienced a negative reaction to your disability by a sex worker/agency?

Have you ever been abused/robbed/manipulated by a sex worker?

Do they stay for the full time you pay for? Do you feel it's value for money?

How do you pay for sex workers? How much?

Was/is using sex workers a moral/religious decision for you?

Have you ever used a sex surrogate/specialist sex worker?

Does the fact that you're paying for a sex worker change/affect the role you play in sex?

Do you feel you have to pay for sex? How does this feel?

'Sex media'

Have you ever used a phone chat/sex line? What were your experiences of these?

Have you ever used porn? Internet/mags/DVD/channel

Have you ever used a live web-based sex service?

Sex

Disability and sex

Do you consider your disability/impairment to influence your enjoyment of sex?

Are there any physical reasons resulting from your impairment that influence your enjoyment of sex? (inc catheters/colostomies)

Do you consider your disability/impairment to influence the role you play in sex?

Are you on any medication that affects sexual function? How does this make you feel?

Are there any particular aspects of sex you enjoy (...)?

Are there any particular aspects of sex you don't enjoy? Why?

Do you use any toys/aids/assistance within sex?

If you do require assistance/facilitation during sex, who provides this, and is this arrangement satisfactory?

Do you use masturbation as part of your sex life?

Sex talk

Do you discuss sex with anyone (other than your partner if you have one)?

Have issues around sex ever been raised with GPs, consultants, OTs (either by you or them)?

Where would you get information on sex if you wanted it?

Do you join in with sex talk with non-disabled men/women?

Do you join in with sex talk with disabled men/women?

References

Abberley, P. (2002) ‘Work, Disability, Disabled People and European Social Theory’. In. C. Barnes et al (2002) *Disability Studies Today*. Cambridge: Polity Press

Abeyesekera, S. (1997) ‘Activism for Sexual and Reproductive Rights: Progress and Challenges’, *Health and Human Rights*, 2: 3, 39-43

Adams, T. E. (2006) ‘Seeking father: Relationally reframing a troubled love story’. *Qualitative Inquiry*, 12: 4, 704-723.

Adams, T.E. (2008) ‘A Review of Narrative Ethics’, *Qualitative Inquiry*, 14: 2, 175-194

Adams, R. (2001) *Sideshow USA: Freaks and the American Cultural Imagination.* USA: University of Chicago Press

Addlakha, R. (2007a) ‘How Young People with Disabilities Conceptualize the Body, Sex and Marriage in Urban India: Four Case Studies ’, *Sexuality and Disability*, 25: 3, 111–123

Albrecht, G., Seelman, K., and Bury, M. (2001) *The handbook of disability studies*. Thousand Oaks, CA: Sage.

Aloni, R. And Katz, S. (2003). *Sexual Difficulties after Traumatic Brain Injury and Ways to Deal with It.* Illinois: Charles C. Thomas.

Anderson, E. M. & Clarke, L. (1982) *Disability in Adolescence*. London: Methuen

Anderson, P. and Kitchen, R. (2000) ‘Disability, space and sexuality: access to family planning services’, *Social Science & Medicine*, 51, 1163-1173

Aphramor, L. (2009) 'Disability and the anti-obesity offensive', *Disability & Society*, 24: 7, 897-909

Appleby, Y. (1992) ‘Disability and `compulsory heterosexuality', *Feminism and Psychology*, 2:3, 502-505

Appleby, Y. (1994) ‘Out on the Margins’, *Disability & Society*, 9: 1, 13-32

Arber, S. And Gilbert, G.N. (1992) *Women and Working Lives: Divisions and Change*. London: Macmillan.

Ariotti, L. (1999) ‘Social construction of Anangu disability’, *Australian Journal of Rural Health*, 7, 216-22.

Arksley, H. and Knight, P. (1999) *Interviewing For Social Scientists: An Introductory Resource with Examples.* London; Thousand Oaks, California: Sage Publications

Armer, B. (2007) ‘Eugenetics: A Polemical View Of Social Policy In The Genetic Age’, *New Formations*, 60, 89-103

Arnot, M. and Dillabough, J. (2000) *Challenging Democracy: Feminist Perspectives on the Education of Citizens*. London: Taylor & Francis

Arundell, T. (1997) ‘Reflections on the Researcher-Researched Relationship: A Woman Interviewing Men’, *Qualitative Sociology*, 20: 3, 341-368

Asch, A., and Fine, M. (1985) ‘Disabled women: sexism without the pedestal’. In Deegan M.J. and Brooks N.A. (eds) *Women and Disability: the Double Handicap*. NewJersey: Transaction Books

Asch, A., and Fine, M. (1988) *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Philadelphia: Temple University Press.

Asch, A., and Fine, M. (1997) ‘Nurturance, sexuality and women with disabilities: The example of women and literature’. In L.J. Davis (Ed.), *The Disability Studies Reader*. New York: Routledge

Atchison, C., Fraser, L., and Lowman, J. (1998) ‘Men Who Buy Sex: Preliminary Findings of an Exploratory Study’. In J. Elias, V. Bullough, V. Elias, and J. Elders (eds) *Prostitution: On Whores, Hustlers, and Johns*. New York: Prometheous Books

Bailey, R. (1996) ‘Prenatal testing and the prevention of impairment: A woman’s right to choose?’ In. J. Morris (ed) *Encounters with Strangers: Feminism and Disability*. London: The Women’s Press Ltd

Ball, K.F. (2002) ‘Who'd Fuck an Ableist?’, *Disability Studies Quarterly*, 22: 4, 166-172

Banks, M. and Kaschak, E. (2003) *Women with Visible and Invisible Disabilities: Multiple Intersections, Multiple Issues, Multiple Therapies*. London: Routledge

Barnes, C. (1991) *Disabled People In Britain*. London: Hurst and Company

Barnes, C. (1992) *Disabling Imagery*. Derby: BCDODP

Barnes, C. (1998) ‘The Social Model of Disability: A sociological phenomenon ignored by sociologists’. In T. Shakespeare (ed.) *The Disability Reader: Social Science Perspectives*. London: Continuum

Barnes, C. et al (2002) *Disability Studies Today*. Cambridge: Polity Press

Barnes, C. (2003) ‘What a difference a decade makes: reflections on doing ‘emancipatory’ disability research’, *Disability and Society*, 18: 1, 3-17.

Barnes, H. (2009) '*Disabled women who pay for sex'*. BBC Ouch. Online. Available from: http://www.bbc.co.uk/ouch/features/disabled_women_who_pay_for_sex.shtml [accessed 2/9/2011]

Barnes, C. and Mercer, G. (1997a) *Doing Disability Research*. Leeds: The Disability Press

Barnes, C. and Mercer, G. (2003) *Disability: Key Concepts*. Cambridge: Polity Press

Barnes, C. and Mercer, G. (2004) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press

Baron, K. (1997) 'The Bumpy Road to Womanhood', *Disability and Society*, 12: 2, 223-240

Barrett S., Komarony C., Robb M. And Rogers A. (2004) *Communication, Relationships and Care: a Reader*. London: Routledge

Bartky, S.L. (1990) *Femininity and Domination: Studies in the Phenomenology of Oppression*. New York: Routledge

Barton, L. (ed) (1996) *Disability and Society: Emerging Issues and Insights*. Harlow: Longman

Barton, L. (2003) 'Challenging Perspectives on Disability and Inclusion'. In K. Heggen, et al (Eds) *Marginalization and Social Exclusion*. Volda: Volda University College

Barton, L. (2005) 'Emancipatory research and disabled people: some observations and questions', *Educational Review*, 57:3, 317-327

Barton, L. and Oliver, M. (1997) *Disability Studies: Past, Present, and Future*. Leeds: The Disability Press

Beazley, S., Moore, M., and Benzie, S. (1997) 'Involving Disabled People in Research: A study of inclusion in environmental activities'. In. Barnes, C. And Mercer, G. (eds) *Doing Disability Research*. Leeds: The Disability Press, 15-31

Begum, N. (1992) 'Disabled Women and the Feminist Agenda', *Feminist Review*, 40, 70-84

Bendelow, G. and Williams, S.J. (1998) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge

Bennet deMarrais, K. (1998) *Inside Stories: Qualitative Research Reflections*. London: Routledge

Beresford, P., Harrison, C., and Wilson, A. (2002) 'Mental health service users and disability: implications for future strategies', *Policy and Politics*, 30, 387-396

Bernstein, E. (2007) *Temporarily Yours: Intimacy, Authenticity and The Commerce Of Sex*. Chicago: University of Chicago Press

Bewley, C. & Glendinning, C. (1994) *Involving Disabled People In Community Care Planning.* London: Joseph Rowntree Foundation

Bland, L. and Doan, L. (1998) *Sexology Uncensored: The Documents of Sexual Science.* Cambridge: Polity Press

Blumenreich, M. (2004) 'Avoiding the pitfalls of 'conventional' narrative research: using poststructural theory to guide the creation of narratives of children with HIV', *Qualitative Research*, 4: 1, 77-90

Blumer, H. (1969) *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice Hall

Blyth, C. (2010) 'Members Only: The Use of Gay Space(s) by Gay Disabled Men', In. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Blythe, C. and Carson, I. (2007) 'Sexual Uncertainties and Disabled Young Men: Silencing Difference Within the Classroom', *PASTORAL CARE*: The Authors Journal compilation NAPCE

Bonnie, S. (2004) 'Disabled People, Disability and Sexuality'. In. J. Swain (ed) *Disabling Barriers, Enabling Environments*. London: Sage Publications Ltd

Bordo, S. (1993) *Unbearable Weight: Feminism, Western Culture, and the Body*. Berkeley: University of California Press

Boris, E., Gilmore, S. And Parreñas, R. (2010) 'Sexual Labors: Interdisciplinary Perspectives Toward Sex as Work', *Sexualities*, 13: 2, 131–137

Branfield, F. (1998) 'What are you doing here? 'Non disabled' people and the disability movement: a response to Robert F. Drake', *Disability and Society*, 13: 1, 143-144.

Brechin, A., Liddiard, P.A., & Swan, J. (1981) *The Handicapped Person in the Community*. London: Open University Press/Tavistock Publications

Breckenridge, C.A. and Vogler, C. (2001) 'The Critical Limits of Embodiment: Disability's Criticism', *Public Culture*, 13: 3, 349-357

Bricher, G. (2000) ‘Disabled People, Health Professionals and the Social Model of Disability: Can There Be A Research Relationship?’ *Disability & Society*, 15: 5, 781-793

Brickell, C. (2006) ‘A Symbolic Interactionist History of Sexuality?’ *Rethinking History*, 10: 3, 415 – 432

Brockmeier, J. And Carbaugh, D. (2001) *Narrative and Identity: Studies in Autobiography, Self, and Culture*. Amsterdam and Philadelphia: John Benjamins

Brown, H. (1994) ‘An Ordinary Sexual Life?: A Review of the Normalisation Principle as it Applies to the Sexual Options of People with Learning Disabilities’, *Disability and Society*, 9: 2, 123-144

Brown, H., Stein, J. & Turk, V. (1995) ‘The sexual abuse of adults with learning disabilities: report of a second two year incidence survey’, *Mental Handicap Research*, 8:1, 1-22.

Browne, J. and Russell, S. (2005) 'My home, your workplace: people with physical disability negotiate their sexual health without crossing professional boundaries', *Disability & Society*, 20:4, 375-388

Brownworth, V.A. and Raffo, S. (1999) *Restricted Access: Lesbians on Disability*. Seal Press: USA

Bruner, J. (1986) *Actual Minds, Possible Worlds*. USA: Harvard University Press

Bryant, J. and Schofield, T. (2007) ‘Feminine Sexual Subjectivities: Bodies, Agency and Life History’, *Sexualities*, 10: 3, 321-340

Bryman, A. (2004) *Social Research Methods*. Oxford: Oxford University Press

Bryman, A. (2008) *Social Research Methods 3rd Edition*. Oxford: Oxford University Press

Bullard, D.G. and Wallace, D.H. (1978) ‘Peer Educator-Counsellors in Sexuality for the Disabled’, *Sexuality and Disability*, 1: 2, 147-152

Bullough, V. (1994) *Science in the Bedroom*. New York: Basic Books

Bulmer, M. (1982) *Social Research Ethics: An Examination Of The Merits Of Covert Participant Observation*. London: Macmillan.

Butler, J. (1990) *Gender Trouble*. London: Routledge

Butler, J. (1993) *Bodies that Matter: On the Discursive Limits of Sex*. London: Routledge

Butler, J. (1997) *Excitable Speech: A Politics of the Performative*. London: Routledge

Bury, M. (2001) ‘Illness narratives: fact or fiction?’, *Sociology of Health & Illness*, 23: 3, 263-285

Brook Advisory Service (2010) *Sex and Disability*. Online. Available from: http://www.brook.org.uk/my-rights/sex-relationships-and-your-rights/sex-and-disability [accessed 2/12/11]

Brown, H. (1994) "An Ordinary Sexual Life?': A Review of the Normalisation Principle as It Applies to the Sexual Options of People with Learning Disabilities', *Disability & Society*, 9: 2, 123-144

Carr, S. (2004) *Has Service User Participation Made A Difference To Social Care Services?* London: Social Care Institute for Excellence

Cacchioni, T. (2007) ‘Heterosexuality and ‘the Labour of Love’: A Contribution to Recent Debates on Female Sexual Dysfunction’, *Sexualities*, 10: 3, 299–320

Califia, P. (1994) *Public sex: The Culture Of Radical Sex*. Pittsburgh: Cleis Press.

Campbell, R. (1998) ‘Invisible Men: making visible male clients of female prostitutes in Merseyside’. In J. Elias, V. Bullough, V. Elias, and J. Elders (eds) *Prostitution: On Whores, Hustlers, and Johns*. New York: Prometheous Books

Campbell, F. K. (2001) ‘Inciting legal fictions: Disability’s date with ontology and the ableist body of the law’. *Griffith Law Review*, 10, 42-62.

Campbell, F.K. (2009) *Contours of Ableism: Territories, Objects, Disability and Desire.* London: Palgrave Macmillan

Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future.* London: Routledge

Cambridge, P. (1996) ‘Men with learning disabilities who have sex with men in public places: mapping the needs of services and users in South East London’, *Journal of Intellectual Disability Research*, 40: 3, 241-251

Campos, L.N. et al (2008) ‘HIV, syphilis, and hepatitis B and C prevalence among patients with mental illness: a review of the literature’, *Review*, S607

Chan, N.K. and Gillick, A. C. (2009) 'Fatness as a disability: questions of personal and group identity', *Disability & Society*, 24: 2, 231-243

Chapkis, W. (1986) *Beauty Secrets: Women And The Politics Of Appearance*. South End: South End Press

Chapkis, W. (1997) *Live sex acts: Women performing erotic labour*. London: Cassell

Cheausuwantavee, T. (2002) 'Sexual Problems and Attitudes Toward the Sexuality of Persons With and Without Disabilities in Thailand', *Sexuality and Disability,* 20: 2, 125-134

Chesser, E. (1950) *Sexual Behaviour: Normal and Abnormal*. London: Hutchinson

Chivers, J and Mathieson, S. (2000) 'Training in Sexuality and Relationships: An Australian Model', *Sexuality and Disability,* 18: 1, 73-80

Clayton, A. H. and Balon, R. (2009) 'Continuing Medical Education: The Impact of Mental Illness and Psychotropic Medications on Sexual Functioning: The Evidence and Management (CME)', *The Journal of Sexual Medicine*, 6: 5, 1200-1211

Coffey, A. and Atkinson, P. (1996) *Making Sense Of Qualitative Data: Complementary Research Strategies.* London: Sage Publications

Connell, R.W. (1995) *Masculinities*. Cambridge: Polity Press

Cooper, C. (1997) 'Can a Fat Woman Call Herself Disabled?', *Disability & Society*, 12: 1, 31-42

Corbett, J. (1994) 'A Proud Label: exploring the relationship between disability politics and gay pride', *Disability and Society*, 9:3, 343-357

Corker, M. (1998) *Deaf and Disabled or deafness Disabled*. Buckingham: Open University Press

Corker, M. (1999) 'Differences, conflations and foundations: the limits to 'accurate' theoretical representation of disabled peoples' experience?', *Disability and Society*, 14: 5, 627-642

Corker, M. and Shakespeare, T. (2002) *Disability/Postmodernity: Embodying Disability Theory*. London: Continuum

Corker, M. and Thomas, C. (2002) 'A Journey Around the Social Model'. In M. Corker and T. Shakespeare (eds) Disability/Postmodernity: Embodying Disability Theory. London: Continuum

Corlyon, J. and McGuire, C. (1997) *Young Parents in Public Care*. London: National Children's Bureau

Courvant, D. (1999) 'Coming Out Disabled: A Transsexual Woman Considers Queer Contributions to Living with Disability', *Journal of Gay, Lesbian, and Bisexual Identity,* 4: 1, 97-105

Craig, L.A. et al (2006) ‘Treating Sexual Offenders With Learning Disabilities in the Community; A Critical Review’, *International Journal of Offender Therapy and Comparative Criminology*, 50: 4, 369-390

Crabtree, L. (1997) ‘Charcot-Marie-Tooth Disease: Sex, Sexuality and Self-Esteem’, Sexuality and Disability, 15: 4, 293-306

Crow, L. (1996) *Rippling raspberries: disabled women and sexuality*. Unpublished MSc dissertation, London, South Bank Polytechnic

Csapo, M. and L. Gougen (1989) ‘Special Education Across Canada: Challenges for the 90's. Vancouver’, *Centre for Human Development and Research*, 199-218

Davy, Z. (2010) ‘A Psycho-social exploration of (Trans) Gender, Sexual Citizenship and Disability: A Case Study’. In. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Davies, D. (2000) ‘Sharing Our Stories, Empowering Our Lives: Don’t Dis Me!’, *Sexuality and Disability*, 18: 3, 179-186

Davis, L. J. (1995) *Enforcing Normalcy: Disability, Deafness, and the Body*. New York: Verso

Davis, L.J. (1997) *The Disability Studies Reader*. New York: Routledge.

Davis, L.J. (2000) ‘Go to the Margins of the Class: Hate Crimes and Disability’. In L. Francis and A. Silvers (eds) *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*. New York: Routledge

Davis, L.J. (2002) *Bending Over Backwards: Disability, Dismodernism, and other Difficult Positions.* New York: New York University Press

Deal, M. (2003) 'Disabled people's attitudes toward other impairment groups: a hierarchy of impairments', *Disability & Society*, 18:7, 897-910

Deegan, M. (1995) ‘Multiple Minority Groups: A Case Study of Physically Disabled Women’. In. M.J. Deegan and N.A. Brooks (eds) Women and Disability: A Double Handicap. London: Transaction Publishers

Deegan, M. & Brooks, M. (1985) *Women and Disability: The Double Handicap*. New Brunswick: Transaction Books

De Graeve, K. (2010) ‘The Limits Of Intimate Citizenship: Reproduction Of Difference In Flemish-Ethiopian ‘Adoption Cultures’, *Bioethics*, 24: 4, 365-372

Dei, G. J. S. and Johal, G. S. (1995) *Critical Issues in Anti-Racist Research Methodologies*. New York: Lang PlC

DeLoach, C., Wilkins, R. And Walker, G. (1983) *Independent Living, Philosophy, Process and Services.* Baltimore: University Park Press

Denov, M. (2003) 'The Myth of Innocence: Sexual Scripts and the Recognition of Child Sexual Abuse by Female Perpetrators', *The Journal of Sex Research*, 40: 3, 303-314

Department for Education and Skills (2009) *Special Education Needs Code of Practice*, Para 9:51. London: DFeS

Descartes, R. (1974) *The Philosophical Works of Descartes*. Trans. E. Haldene, and G. Ross. Cambridge: Cambridge University Press

DeVault, M. L. (1999) 'Comfort and Struggle: Emotion Work in family Life', *The ANNALS of the American Academy of political and Social Science*, 561, 52-63

Dewsbury, G. Et al. (2004) 'The anti--social model of disability', *Disability & Society*, 19:2, 145-158

Dickson-Smith, V. et al (2009) 'Researching sensitive topics: qualitative research as emotion work', *Qualitative Research*, 9: 1, 61-79

Dickson-Smith, V. et al (2009) 'Researching sensitive topics: qualitative research as emotion work', *Qualitative Research*, 9: 1, 61-79

Disability Now (2005) *Results of Time to Talk Sex Survey*, May. London: Disability Now

Drench, M. (1992) 'Impact of altered sexual function in spinal cord injury', *Sex and Disability*, 10, 3-14

Duckett, P.S. and Pratt, R. (2001) 'The Researched Opinions on Research: visually impaired people and visual impairment research', *Disability & Society*, 16: 6, 815–835

Dukes, E. & McGuire, B. E. (2009) 'Enhancing capacity to make sexuality-related decisions in people with an intellectual disability', *Journal of Intellectual Disability Research*, 53: 8, 727-734

Duncombe, J. and Marsden, D. (1998) 'Stepford wives' and 'hollow men'?: doing emotion work, gender and 'authenticity' in intimate relationships. In G. Bendelow and S.J. Williams (Eds.) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge

Dune, T. M. and Shuttleworth, R.P. (2009) '"It's Just Supposed to Happen'': The Myth of Sexual Spontaneity and the Sexually Marginalized', *Sexuality and Disability*, 27, 97–108

Earle, S. (1999) 'Facilitated Sex and the Concept of Sexual Need: disabled students and their personal assistants', *Disability and society*, 14: 3, 309-323

Earle, S. (2001) 'Disability, Facilitated Sex and the Role of the Nurse', *Journal of Advanced Nursing*, 36: 3, 433-440

Elias, J., Bullough, V., Elias, V. and Elders, J. (1998) *Prostitution: On Whores, Hustlers, and Johns*. New York: Prometheous Books

Ellis, H. (1927) *Studies in the Psychology of Sex,* (Vol. 3): *Analysis of the Sexual Impulse, Love and Pain, The Sexual Impulse in Women*. Philadelphia: D.A. Davies

Engelsrud, G. (2005) 'The lived body as experience and perspective: methodological challenges', *Qualitative Research*, 5: 3, 267-284

Erevelles, N. (2005) 'Understanding curriculum as normalising text: disability studies meets curriculum theory', *Journal of Curriculum Studies*, 37: 4, 421-439

Eunjung, K. (2011) 'Asexuality in disability narratives', *Sexualities*, 14: 4, 479-493

Evans, M. and Lee, E. (2002) *Real Bodies: A Sociological Introduction*. Hampshire: Palgrave

Exley, C. and Letherby, G. (2001) 'Managing a Dirupted Lifecourse: Issues of identity and Emotion Work', *Health*, 5: 1, 112-132

Fanon, F. (1993) *Black Skin, White Masks*. London: Pluto Press

Fetterman, D.M. (1991*) Using Qualitative Methods in Institutional Research*. San Francisco: Jossey-Bass.

Finch, J. and Groves, D. (1983) *A Labour of Love: Women, Work and Caring*. London: Routledge and Kegan Paul.

Finger, A. (1992) 'Forbidden fruit'. *New Internationalist*, 233: 8–10

Finklestein, V. (1980) *Attitudes and Disabled People: issues for discussion*. New York: World Rehabilitation Fund

Flood, R. and Gill, R. (2009) *Secrecy and silence in the research process: feminist reflections*. Ryan- Abingdon, Oxon; New York, NY: Routledge

Foucault, M. (1976) *The History of Sexuality,* Vol. 1: *An Introduction*. Harmondsworth: Penguin

Foucault, M. (1985) *The Use of Pleasure: The History of Sexuality*, Vol. 2. Harmondsworth: Penguin

Foucault, M. (1986) *The Care of the Self: The History of Sexuality*, Vol. 3.

Harmondsworth: Penguin

Francis, L. and Silvers, A. (2000) *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*. New York: Routledge

Frank, A.W. (1995) *The Wounded Storyteller: Body Illness, and Ethics.* Chicago and London: The University of Chicago Press Ltd

Fraser, M. (1999) 'Classing Queer: Politics in Competition', *Theory, Culture and Society*, 16: 2, 107-131

French, S. (1993) *Disabling Barriers-Enabling Environments*. London: Sage

Friedman, S.H., and Loue, S. (2007) 'Incidence and prevalence of intimate partner violence by and against women with severe mental illness', *Journal of Women's Health*, 16: 4, 471-480

Frogatt, K. (1998) 'The place of metaphor and language in exploring nurses' emotional work', *Journal of Advanced Nursing*, 28: 2, 332-338

Gabel, S. and Peters, S. (2004) 'Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability', *Disability & Society*, 19: 6, 585-600

Gagnon, J. and Simon, W. (1969) 'Psychosexual development Men and women play the sexual drama according to a post-Freudian script', *Society*, 6: 5, 9-17

Gagnon, J. & Simon, W. (1974) *Sexual Conduct*. London: Hutchison

Galvin, R.D. (2005) 'Researching the disabled identity: contextualising the identity transformations which accompany the onset of impairment', *Sociology of Health & Illness*, 27: 3, 393-413

Galvin, R. (2006) 'A genealogy of the disabled identity in relation to work and sexuality', *Disability and Society*, 21:5, 499 — 512

Garbutt, R. (2010) 'Exploring the barriers to Sex and Relationships for People with Learning Difficulties'. In R. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Garland-Thompson, R. (2002) 'Integrating Disability, Transforming Feminist Theory', *Feminist Formations*, 14: 3, 1-32

Gerschick, T.J. (1995) 'Toward a theory of disability and gender', *Signs*, 25: 4, 1263-1268

Gerschick T.J., Miller A.S., (1995) ‘Coming to terms’. In *Men's Health and Illness*. D.Sabo & D. Gordon (eds) London: Sage

Ghai, A. (2002) ‘Disabled Women: An Excluded Agenda of Indian Feminism’, *Hypatia*, 17: 3, 49-66

Ghai, A. (2006) ‘(*Dis)embodied Form: Issues for Disabled Women*. Delhi: Shakti Books

Giddens, A. (1992) *The Transformation of Intimacy: Sexuality, Love and Eroticism in Modern Societies*. Cambridge: Polity Press

Gillespie-Sells, K. et al (1998) *She Dances to Different Drums*. London: King’s Fund

Glasby, J. and Littlechild, R. (2009) *Direct Payments and Personal Budgets: Putting Personalisation into Practice.* Bristol: The Policy Press

Goffman, E. (1963) *Stigma: notes on the management of social identity*. Harmondsworth: Penguin

Goodley, D. (2010) *Disability Studies: An Interdisciplinary Introduction*. London, California, New Delhi and Singapore: Sage Publications Ltd

Goodley, D. (2011) ‘Social psychoanalytic disability studies’, *Disability & Society*, 26:6, 715-728

Goodley, D. And McLaughlin, J, (2011) *Does Every Child Matter, Post-Blair? The Interconnections of Disabled Childhoods* ESRC End of Award Report, RES-062-23-1138. Swindon: ESRC

Goodley, G. and Runswick-Cole (2011) *‘Does Every Child Matter, post-Blair? Accessible end of project report’* Online. Available from: www.rihsc.mmu.ac.uk/postblairproject/ [accessed 10/12/11]

Goodley and Runswick-Cole (2011) *‘Does Every Child Matter, Post-Blair? The interconnections of disabled childhoods website’ Online*. Available from: http://post-blair.posterous.com/pages/publications [accessed 13/12/11]

Goodley, D. and Tregaskis, C, (2006) ‘Storying Disability and Impairment: Retrospective Accounts of Disabled Family Life’, *Qualitative Health Research*, 16: 5, 630-646

Graham, H. (1983) ‘Caring: A Labour of Love’, In J. Finch and D. Groves (eds) *A Labour of Love: Women, Work and Caring*. London: Routledge and Kegan Paul.

Griffiths, M. (2006) Sex: *Should We All Be At it? A Study into the Struggles of Disabled Peoples’ Fight For Sexual Expression, and the Implications of Using*

Prostitutes and Surrogates to Facilitate This Sexual Expression. Sociology Dissertation, University of Leeds, Leeds

Guldin, A. (2000) 'Self-claiming sexuality: mobility impaired people and American culture', S*ex and Disability*, 18: 4, 233–238

Hahn, H. (1981) 'The social component of sexuality and disability: some problems and proposals', *Sexuality and Disability*, 4: 4, 220-33

Hahn, H. (1988). Can disability be beautiful? *Social Policy*, 18:3, pp. 26-32.

Hales, G. (1995) *Beyond Disability*. London: Sage

Hamam, N., McCluskey, A. and Shuttleworth, R. (2009) '*Sexual Adaptation in Adults with Physical Impairment'*. Inaugeral Conference for OT Australia NSW-ACT, Sydney, Australia

Hamilton, C.A. (2009) "Now I'd like to sleep with Rachael' - researching sexuality support in a service agency group home', *Disability & Society*, 24: 3, 303 — 315

Haraway, D. (1991) *Simians, Cyborgs and Women: The Reinvention of Nature*. London: Free Association Books

Hassouneh-Phillips, D. and McNeff, E. (2004) "I Thought I was Less Worthy": Low Sexual and Body Esteem and Increased Vulnerability to Intimate Partner Abuse in Women with Physical Disabilities', *Sexuality and Disability*, 23: 4, 227-240

Hassouneh-Phillips, D., McNeff, E. (2005) "I thought I was less worthy": Low Sexual and Body Esteem and Increased Vulnerability to Intimate Partner Abuse in Women with Physical Disabilities', *Disability and Sexuality*, 23: 4, 227-240

Hawkes, G. (1996) *A Sociology of Sex and Sexuality*. Buckingham: Open University Press

Heggen, K. et al (2003) *Marginalization and Social Exclusion*. Volda: Volda University College

Henderson, A. (2001) 'Emotional labour and nursing: an under-appreciated aspect of caring work', *Nursing Inquiry*, 8: 2, 130-138

Hicks, S. (1981) 'Relationship and Sexual Problems of the Visually Handicapped'. In. A. Brechin, P.A. Liddiard, & J. Swan (1981) *The Handicapped Person in the Community*. London: Open University Press/Tavistock Publications

Hochschild, A.R. (1979) 'Emotion Work, Feeling Rules, and Social Structure', *The American Journal of Sociology*, 85: 3, 551-575

Hochschild, A.R. (1983) *The Managed Heart: Commercialization of Human Feeling*. Berkeley, Los Angeles, London: University of California Press

Hodge, N. (2008) 'Evaluating Lifeworld as an emancipatory methodology', *Disability & Society*, 23: 1, 29-40

Heigard, C. and Finstad, L. (1992) *Backstreets: Prostitution, Money, and Love*. University Park: The Pennsylvania State University Press

Holland, J., Ramazanoglu, C., Sharpe, S. And Thomson, R. (1998) *The Male in the Head: young people, heterosexuality and power*. London: The Tuffnell Press

Hollomotz, A. (2010) 'Sexual 'vulnerability' of People with Learning Difficulties: A Self-Fulfilling Prophecy', In. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Hollway 1994

Hollway, W. (1996) 'Gender Difference And The Production Of Subjectivity'. In S. Jackson and S. Scott. (eds) *Feminism and Sexuality: a reader*. USA: Columbia University Press

Holt, T.J. and Blevins, K.R. (2007) 'Examining Sex Work From The Client's Perspective: Assessing Johns Using On-Line Data', *Deviant Behavior*, 28, 333-354, 2007

Holzman, H.R. and Pines, S. (1982) 'Buying Sex: The Phenomenology of Being a John', *Deviant Behavior*, 4, 89-116.

Howland, C.A. and Rintala, D.H. (2001) 'Dating Behaviors of Women with Physical Disabilities', *Sexuality and Disability*, 19: 1, 41-70

Hughes, E. & Gray, R. (2009) "HIV prevention for people with serious mental illness: A survey of mental health workers' attitudes, knowledge and practice", *Journal of Clinical Nursing*, 18: 4, 591-600

Hughes, B. and Paterson, K. (1997) 'The Social Model of Disability and the Disappearing Body: towards a sociology of impairment', *Disability & Society*, 12: 3, 325 — 340

Hughes, B. et al (2005) 'Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care', *Sociology*, 39: 2, 259-275

Hunt, P. (1981.) 'Settling accounts with the parasite people: A critique of 'A Life Apart' by E.J. Miller and G.V. Gwynne'. *Disability Challenge*, 1: 37-50.

Intimaterider.com (2011) *Intimate Rider*. Online. Available from: http://www.intimaterider.com/ [accessed 14/12/11]

Jackson, S. and Scott, S. (1996) *Feminism and Sexuality: a reader*. USA: Columbia University Press

Jackson, S. and Scott, S. (1997) 'Gut reactions to matters of the heart: reflections on rationality, irrationality and sexuality', *The Editorial Board of The Sociological Review*. Oxford and Malden: Blackwell Publishers

Jackson, S. (1999) *Heterosexuality in Question*. London: Sage Publications Ltd

Jackson, S. and Scott, S. (2010) *Theorizing Sexuality*. Berkshire: Open University Press

James, N. (1992) 'Care = organisation + physical labour + emotional labour', *Sociology of Health and Illness*, 14: 4, 488-509

Janesick, V.J. (1998) 'A Journal About Journal Writing as a Qualitative Research Technique: History, Issues, and Reflections', *Qualitative Inquiry*, 5: 4, 505-524

Jeffreys, J. (1994) 'The queer disappearance of lesbians: Sexuality in the academy', *Women's Studies International Forum*, 17: 5, 459-472

Jeffreys, S. (2008) 'Disability and the male sex right', *Women's Studies International Forum*, 31, 327–335

Jennes, V. (1990) 'From Sex as Sin to Sex as Work: COYOTE and the Reorganization of Prostitution as a Social Problem', *Social Problems*, 37: 3, 403-420

Jewkes, Y. (2003) *Dot.Cons: Crime, Deviance And Identity On The Internet*. Cullompton, UK: Willan

Jokinen, E. (2004) 'The Makings of Mother in Diary Narratives', *Qualitative Inquiry*, 10: 3, 339-359

Kafer, A. (2003) 'Compulsory Bodies: Reflections on heterosexuality and Able-Bodiedness', *Journal of Women's History*, 15: 3, 77-89

Kanguade, G. (2010) 'Advancing Sexual Health of Persons with Disabilities through Sexual Rights: The Challenge'. In. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Kantola, J. and Squires, J. (2004) 'Discourses Surrounding Prostitution Policies in the UK', *European Journal of Women's Studies*, 11: 1, 77-101

Keith, L. (1990) 'Caring Partnership', *Community Care*, 22 February, v-vi

Keith, L. (1996) 'Encounters with strangers: the public's responses to disabled women and how this affects our sense of self, in J. Morris (ed) *Encounters With Strangers: feminism and disability*. London: Women's Press

Keith, L. And Morris, J. (1995) ‘Easy targets: a disability rights perspective on the ‘children as carers’ debate’. In J. Morris (ed) *Encounters With Strangers: feminism and disability*. London: Women’s Press

Kelly, M.P. and Field, D. (1996) ‘Medical sociology, chronic illness and the body’, *Sociology of Health and Illness, 18: 2, 241-257*

Kent, D. (2002) ‘Beyond Expectations: Being Blind and Becoming a Mother’, *Sexuality and Disability*, 20: 1, 81-88

Kimmel, M. (2007) *The Sexual Self: The Construction of Sexual Scripts*. Nashville: Vanderbilt University Press

Kinsey A.C., Pomeroy W.B., and Martin C.E. (1948) *Sexual Behavior in the Human Male*. Philadelphia: W. B. Saunders Co.

Kinsey, A.C. (1953) *Sexual Behavior in the Human Female*. London: W. B. Saunders Co

Kitchen, R. (2000) ‘The Researched Opinions on Research: disabled people and disability research’, *Disability and Society*, 15: 1, 25-47

Kitchin, R. (2001) ‘Using participatory action research approaches in geographical studies of disability: Some reflections’. *Disability Studies Quarterly*, 24: 4, 61-69.

Kitchin, R. (2000) ‘The Researched Opinions on Research: disabled people and disability research’, *Disability & Society*, 15: 1, 25-47

Koch, T. (2000) ‘Life quality vs. the ‘quality of life’: assumptions underlying prospective quality of life instruments in health care planning’, *Social Science & Medicine*, 51: 3, 419-427

Kohrman, M. (2008) ‘Grooming quezi: marriage exclusion and identity formation among disabled men in contemporary China’, *American Ethnologist*, 26: 4, 890-909

Komisaruk, B.R., Beyer, C., and Whipple, B. (2006) *The Science of the Orgasm*. Liverpool: The Johns Hopkins University Press

Korczynski, M. (2003) ‘Communities of Coping: Collective Emotional Labour in Service Work’, *Organization*, 10: 1, 55-79

Krafft-Ebing, R.V. (1899) *Psychopathia Sexualis: With Especial Reference to Antipathetic Sexual Instincts: A Medico-Forensic Study*. London: Rebman

Krotoski, D.M., Nosek, M.A., and Turk, M.A (eds) (1996) *Women with Physical Disabilities: Achieving and Maintaining Health and Well-being*. Baltimore, MD: Paul H. Brooks

Langellier, K. (2001) ‘‘You’re Marked’: Breast Cancer, Tattoo and the Narrative Performance of Identity.’ In J. Brockmeier and D. Carbaugh. (eds) *Narrative and Identity: Studies in Autobiography, Self, and Culture*. Amsterdam and Philadelphia: John Benjamins

Laws, J.L. and Schwartz, P. (1977) *Sexual Scripts: The Social Construction of Female Sexuality*. Hinsdale, IL: Dryden

Laxton, C. and Goldworthy, A. (2008) *Up Close and Personal: A report into disabled and non disabled people’s attitudes and experiences of relationships in the UK*. London: Leonard Cheshire Disability

LeCompte, M.D. (1993) ‘A Framework for Hearing Silence: What Does Telling Stories Mean When We are Supposed to be Doing Science?’ in D. McLaughlin and W.G. Tierney (eds) *Naming Silenced Lives: Personal Narratives and Processes of Educational Change*, pp. 9–28. New York: Routledge

Leder, D. (1990) *The Absent Body*. Chicago and London: The University of Chicago Press Ltd

Lee, R.M. (1993) *Doing Research on Sensitive Topics*. London: Sage Publications

Lee, O.E.K. and Heykyung, O. (2005) ‘A Wise Wife and Good Mother: Reproductive Health and Maternity Among Women with Disability in South Korea’, *Sexuality and Disability*, 23: 3, 121-144

Lees, S. (2000) ‘Sexuality and Citizenship Education’. In. M. Arnot and J. Dillabough (eds) *Challenging Democracy: Feminist Perspectives on the Education of Citizens*. London: Taylor & Francis

Lee-Treweek G. (1997) 'Women, Resistance and Care: An Ethnography of Nursing Auxiliary Work', *Work, Employment and Society*, 11: 1, 47-63

Leibowitz, R.Q. (2005) ‘Sexual Rehabilitation Services after Spinal Cord Injury: What Do Women Want? *Sexuality and Disability*, 23: 2, 81-107

Leonard Cheshire Disability (2011) *In Touch.* Online. Available from: http://www.lcdisability.org/?lid=9439 [accessed 4/9/11]

Li, C.M. and Yau, M.K. (2006) ‘Sexual Issues and Concerns: Tales of Chinese Women with Spinal Cord Impairments’, *Sexuality and Disability*, 24: 1, 1-26

Light, R. (2000) ‘Disability theory: social model or unsociable muddle?’ *Disability Tribune*, December 1999/January 2000, 10–13

Lindsay, W.R. et al (1998) 'The treatment of six men with a learning disability convicted of sex offences with children', *British Journal of Clinical Psychology*, 37: 1, 83-98

Lloyd, M. et al (1996) 'Whose Project is it Anyway? Sharing and shaping the research and development agenda', *Disability & Society*, 11: 3, 301-315

Lloyd, M. (2001) 'The Politics of Disability and Feminism: Discord or Synthesis?', *Sociology*, 35: 3, 715-728.

Lonsdale, S. (1990) *Women and Disability: the experience of disability among women*. Basingstoke: Macmillan

Lunsky, Y. et al (2007) 'Sexual knowledge and attitudes of men with intellectual disability who sexually offend', Journal of Intellectual and Developmental Disability, 32: 2, 74-81

Lupton, D. (1996) 'Constructing the Menopausal Body: The Discourses on Hormone Replacement Therapy, *Body and Society*, 2: 1, 91-91

Mairs, N. (1996) *Waist-High in the World: A Life Among the Nondisabled*. Boston: Beacon

Marks, D. (1997) 'Models of Disability', *Disability and Rehabilitation*, 19: 3, 85-91

Marks, D. (1999): 'Dimensions of Oppression: Theorising the embodied subject', *Disability & Society*, 14:5, 611-626

Marshall, Barbara & Katz, Stephen (2002) 'Forever functional: sexual fitness and the ageing male body', *Body& Society*, 8; 4, 43–70.

Mason, M. (1992) A nineteen-parent family. In J. Morris (ed.) *Alone Together: Voices of Single Mothers.* London: The Women's Press

Masters W.H., Johnson E.J. (1966) *Human Sexual Response*. Boston: Little, Brown and Company.

Masters, W. H., & Johnson, V. E. (1966) *Human Sexual Response*. London: Churchill

Masters, W.H. and Johnson, V.E. (1974). *The Pleasure Bond*. Toronto; New York: Bantam Books

Masters, W.H. and Johnson, V. (1986) *On Sex and Human Loving*. Boston, MA: Little Brown

McCabe, P.M., Cummins, R. A., and Deeks, A.A. (2000) 'Sexuality and Quality of Life Among People with Physical Disability', Sexuality *and Disability*, 18: 2, 115-123

McCabe, M.P. and Taleporos, G. (2003) 'Sexual Esteem, Sexual Satisfaction, and Sexual Behavior Among People With Physical Disability', *Archives of Sexual Behavior*, 32: 4, 359–369

McCarthy, M. (1996) 'The sexual support of people with learning disabilities: a profile of those referred to sex education', *Sexuality and Disability*, 14: 4, 265-279

McCarthy, M. (1998) 'Interviewing People with Learning Disabilities about Sensitive Topics: A Discussion of Ethical Issues', *British Journal of Learning Disabilities*, 24: 4, 140-145

McCarthy, M. (1999) *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers

McCarthy, M. and Thompson, D. (1996) 'Sexual Abuse by Design: An Examination of the Issues in Learning Disability Services', *Disability and Society*, 11: 2, 205-217

McCormick, N.B. (1999) 'When Pleasure Causes Pain: Living with Interstitial Cystitis', *Sexuality and Disability*, 17: 1, 7-18

McKeganey, N., & Barnard, M. (1996) *Sex work on the streets*. Buckingham: Open University Press

McLaughlin, D. and Tierney, W.G. (1993) *Naming Silenced Lives: Personal Narratives and Processes of Educational Change*, pp. 9–28. New York: Routledge

McRuer, R. (2006) 'We Were Never Identified: Feminism, Queer Theory, and a Disabled World', *Radical History Review*, 94, 148-54

McRuer, R. (2006) *Crip Theory: Cultural Signs of Queerness and Disability*. New York and London: New York University Press

McRuer, R. (2002) 'Critical Investments: AIDS, Christopher Reeve, and queer/disability studies', *Journal of Medical Humanities*, 23: 3, 221-237

Meekosha, H. (1998) 'Body Battles: Bodies, Gender and Disability'. In T. Shakespeare, (ed.) *The Disability Reader*. London: Continuum International Publishing Group Ltd

Meekosha, H. and Shuttleworth, R. (2009) What's so 'critical' about critical disability studies*? Australian Journal of Human Rights,* 15: 1, 47–76.

Merleau-Ponty, M. (1962) *The Phenomenology of Perception*. London: Routledge

Milligan, M. and Neudfeldt, A. (2001) 'The Myth of asexuality: a survey of social and empirical evidence', *Sexuality and Disability,* 4, 91-109

Millward, L.J. (1995) 'Contextualising social identity in considerations of what it means to be a nurse', *European Journal of Psychology*, 25, 303-324

Michalko, R. (2002) *The Difference that Disability Makes*. Philadelphia, PA: Temple University Press

Michie, A.M. et al (2006) 'A Test of Counterfeit Deviance: A Comparison of Sexual Knowledge in Groups of Sex Offenders with Intellectual Disability and Controls', *Sexual Abuse: A Journal of Research and Treatment*, 18: 3, 271-278

Milberger S., Israel N., LeRoy B., and Martin A. (2003) 'Violence against women with physical disabilities', *Violence and Victims,* 18: 5, 581–91

Mona, L.R., Gardos, P.S. and Brown, R.C. (1994) 'Sexual Self Views of Women with Disabilities: The Relationship Among Age-of-Onset, Nature of Disability and Sexual Self-Esteem', *Sexuality and Disability,* 12: 4, 261-277

Mona, L.R. (2003) 'Using Personal Assistance Services for Sexual Expression'. In M. Banks and E. Kaschak (eds) *Women with Visible and Invisible Disabilities: Multiple Intersections, Multiple Issues, Multiple Therapies*. London: Routledge

Monto, M. A. (2000) 'Why Men Seek Out Prostitutes'. In R. Weitzer (ed.) *Sex For Sale.* London: Routledge

Morris, J. (1989) *Able Lives: Women's experience of paralysis*. London: The Women's Press Ltd

Morris, J. (1991) *Pride Against Prejudice: Transforming Attitudes to Disability*. Philadelphia, PA: New Society Publishers

Morris, J. (1992) *Alone Together: Voices of Single Mothers.* London: The Women's Press

Morris, J. (1993) *Independent Lives?: Community care and disabled people*. London: Macmillan

Morris, J. (1996) *Encounters With Strangers: feminism and disability*. London: Women's Press

Morris, J. (1997) 'Care or Empowerment? A Disability Rights Perspective', *Social Policy and Administration*, 31: 1, 54-60

Morris, J. (1998) '*Feminism, gender and disability'*. Paper presented at a seminar in Sydney, Australia: February

Morris, J. (2001) ‘Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights’, *Hypatia*, 16: 4, 1-16

Murphy, R. (1990) *The Body Silent*. New York: W.W. Norton

Neal, S. (1999) ‘Researching Powerful People from a Feminist and Anti-racist Perspective: a note on gender, collusion and marginality’, *British Educational Research Journal*, 21: 4, 517-531

Nelson, D. (2007) ‘Women, Sex and Disability - A Triple Taboo.’ *Disability Knowledge and Research*, 1-2, London: HealthLink Worldwide

Nicolson, N. and Burr, J. (2003) ‘What is ‘normal’ about women’s (hetero)sexual desire and orgasm?: a report of an in-depth interview study’, *Social Science & Medicine*, 57, 1735-1745

Noonan, R.J. (1984) ‘*Sex Surrogates: A Clarification Of Their Functions’*. MA Dissertation, Submitted in the Department of Health Education, School of Education, Health, Nursing, and Arts Professions, New York University,

Nosek, M. (2001) ‘Vulnerabilities for abuse among women with disabilities’, *Sexuality and Disability*, 19: 3, 177–190

Oakley, A. (1993) *Essays on Women, Medicine and Health*. Edinburgh: Edinburgh University Press

O’Brien, M. (1990) ‘On Seeing a Sex Surrogate’, *The Sun*, May, issue #174

O'Callaghan, A.C and Murphy, G.H. (2007) ‘Sexual relationships in adults with intellectual disabilities: understanding the law’, *Journal of Intellectual Disability Research*, 51: 3, 197-206

O’Connell-Davidson, J. (2002) ‘The Rights and Wrongs of Prostitution’, *Hypatia*, 17: 2, 84-98

Davidson, J. O., (2003) `Sleeping with the Enemy'? Some Problems with Feminist Abolitionist Calls to Penalise those who Buy Commercial Sex’, *Social Policy and Society*, 2: 1, 55-64

Ogbonna, E. and Harris, L.C. (2004) ‘Work Intensification and Emotional Labour Among UK University Lecturers: An Exploratory Study’, *Organization Studies*, 25: 7, 1185-1203

Oleksy, E.H. (2009) *Intimate Citizenships: Gender, Sexualities, Politics*. London: Routledge

Oliver, M. (1990) *The politics of disablement.* Basingstoke: Macmillian

Oliver, M. (1992) ‘Changing the social relations of research production’, *Disability and Society*, 11, 115-120

Oliver, M. (1997) ‘Emancipatory Research: Realistic goal or impossible dream?’. In. Barnes, C. And Mercer, G. (eds) *Doing Disability Research*. Leeds, The Disability Press

Oliver, M. and Barnes, C. (1997) ‘All we are saying is give disabled researchers a chance’, *Disability and Society*, 12: 5, 811-813

Olkin, R. (2002) ‘Could you hold the door for me? Including disability in diversity’, *Cultural Diversity and Ethnic Minority Psychology*, 8: 2, 130-137

Olsen, R. and Clarke, H. (2003) *Parenting And Disability: Disabled Parents’ Experiences Of Raising Children*. Bristol: Policy Press

Oriel, J. (2005) ‘Sexual pleasure as a human right: Harmful or helpful to women in the context of HIV/AIDS?’, *Women’s Studies International Forum*, 28, 392– 404

Ostrander, N. (2009) ‘Sexual Pursuits of Pleasure among Men and Women with Spinal Cord Injuries’, *Sexuality and Disability*, 27, 11-19

O’Connell-Davidson, J. (1998) *Prostitution, power and freedom*. Cambridge: Polity.

O’Toole, C. (2002) ‘Sex, Disability and Motherhood: Access to Sexuality for Disabled Mothers’, *Disability Studies Quarterly*, 22: 4, 87-108

O’Toole, C.J. (2000) ‘The View from Below: Developing a Knowledge Base About an Unknown Population’, *Sexuality and Disability*, 18: 3, 207-224

O’Toole, C.J., and Doe, T. (2002) ‘Sexuality and Disabled Parents With Disabled Children’, *Sexuality and Disability*, 20; 1, 89-101

Outshoorn, J. (2001) ‘Debating Prostitution in Parliament: A Feminist Analysis’, *The European Journal of Women’s Studies*, 8: 4, 472–490

Overboe, J. (2007a) ‘Disability and Genetics: Affirming the Bare Life (the State of Exception)*’, *CRSAIRCSA*, 44: 2, 220-235

Parker, G. (1993) ‘A four-way stretch? The politics of disability and caring’, in Swain, J., et al. (eds), *Disabling Barriers: Enabling Environments*. London: Sage.

Parker, M.G. and Yau, M.K. (2011) ‘Sexuality, Identity and Women with Spinal Cord Injury’, *Sexuality and Disability*, Online Publishing Preview

Pateman, C. (1988) *The Sexual Contract*. Cambridge: Polity.

Paterson, K. And Hughes, B. (1997) 'The Social Model of Disability and the Disappearing Body: towards a sociology of impairment', *Disability & Society*, 12: 3, 325- 340

Parckar, G. (2008) *Disability Poverty in the UK*. London: Leonard Cheshire Disability

Pearson and Klook (1989) 'Sexual Behaviour Following Paraplegia: an exploratory study in Hong Kong', *Disability and Society*, 4: 4, 285-295

Peng, Y.W. (2007) 'Buying Sex. Domination and Difference in the discourses of Taiwanese piao-ke', *Men and Masculinities*, 9: 3, 315-36

Perry, B.L. and Wright, E.R. (2006) 'The sexual partnerships of people with serious mental illness', *Journal of Sex Research*, 43: 2, 174-181

Petcheskey, R.P. (2000) 'Rights and Needs: Rethinking the Connections in Debates over Reproductive and Sexual Rights', *Health and Human Rights*, 4: 2, 17-29

Phillips, S. (2010) 'Disability, Masculinity, and Sexuality in Post-Soviet Ukraine'. In. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Plummer, K. (1975) *Sexual Stigma: An Interactionist Account*. London: Routledge and Keagan Paul

Plummer, K. (1995) *Telling Sexual Stories: Power, Change and Social Worlds*. London: Routledge

Plummer, K. (2003) *Intimate Citizenship: Private Decision and Public Dialogues*. Seattle and London: University of Washington Press

Plummer, K. (2008) 'Studying Sexualities for a Better World? Ten Years of Sexualities', *Sexualities*, 11: 1-2, 7-22

Pole and Lampard (2002) *Practical Social Investigation: Qualitative and Quantitative Methods in Social Research*. Essex: Pearson Education Ltd

Potts, A. (2000) '"The Essence of the Hard On": Hegemonic Masculinity and the Cultural Construction of "Erectile Dysfunction", *Men and Masculinities*, 3: 1, 85-103

Pothier, D. and Devlin, R. (2006) *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*. London: UBC Press

Powers, L.E., Curry, M.A., Oschwald, M., Maley, S., Saxton, M, and Eckels, K. (2002) 'Barriers and strategies in addressing abuse: A survey of disabled women's Experiences', *Journal of Rehabilitation*, 68: 1, 4-13.

Prillelltensky, O. (2003) ‘A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities’, *Sexuality and Disability*, 21: 1, 21-47

Ramazanoglu, C. (1993) *Up Against Foucault*. London: Routledge

Raymond, J. G. (2004) ‘Prostitution on Demand: Legalizing the Buyers as Sexual Consumers’, *Violence Against Women*, 10: 10, 1156-1186

Reeve, D. (2002) ‘Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity constructions’, *Disability and Society*, 17: 5, 493-508

Reeve, D. (2004) ‘Psycho-emotional Dimensions of Disability and the Social Model’, In C. Barnes and G. Mercer (eds) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press

Reich, J.A. (2003) ‘Pregnant with Possibility: Reflections on Embodiment, Access, and Inclusion in Field Research’, *Qualitative Sociology*, 26: 3, 351-367

Reinharz, S. (1985). Feminist distrust: A response to misogyny and gynopia in sociological work. In. Feminist distrust: Problems of context and content in sociological work. In D. Berg & K. Smith (Eds.), Clinical demands of social research. Beverly Hills, CA.: Sage.

Reiter, R. (1975) *Toward an Anthropology of Women*. New York: Monthly Review Press

Riessman, C, K. (2003) ‘Narrative Analysis’, In M.S. Lewis-Beck, A. Bryman and T. Futing Liao (eds.) *The Sage Encyclopedia of Social Science Research Methods*, Vol. 3. London: Sage

Rembis, M.A. (2010) ‘Beyond the Binary: Rethinking the Social Model of Disabled Sexuality’, Sexuality and Disability, 28, 51–60

Renzetti, C.M. (1993) *Researching Sensitive Topics*. California: Sage Publications

Reynolds, D. (2007) ‘Disability and BDSM: Bob Flanagan and the Case for Sexual Rights’, *Sexuality Research & Social Policy*, 4: 1, 40-52

Reynolds, P. (2010) ‘Disentangling Privacy And Intimacy: Intimate Citizenship, Private Boundaries And Public Transgressions’, *Human Affairs*, 20, 33-42

Rich, A. (1989) ‘Compulsory heterosexuality and lesbian existence’. In L. Richardson & V. Taylor (Eds) *Feminist Frontiers II: Rethinking sex, gender and society*. New York: Random House

Richardson, L. & Taylor, V. (1989) *Feminist Frontiers II: Rethinking sex, gender and society* New York: Random House

Richardson J.T. (1996) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences* Leicester: BPS Books

Richardson, D. (1996) *Theorising Sexuality*. Buckingham, UK: Open University

Richardson, D. (1998) 'Sexuality and Citizenship', *Sociology*, 32: 1, 83-100

Richardson, D. (2000) 'Constructing sexual citizenship: theorizing sexual rights', *Critical Social Policy*, 20: 1, 105-135

Rintala, D.H. et al (1997) 'Dating Issues for Women with Physical Disabilities', *Sexuality and Disability*, 15: 4, 219-242

Rioux, M. and Bach, M. (1994) *Disability is Not Measles: New Directions in Disability*. Ontario: L'Institut Roeher

Roberts, H. (1981) *Doing Feminist Research*. London: Routledge and Kegan Paul

Rock, P.J. (1996) 'Eugenics and Euthanasia: A cause for concern for disabled people, particularly disabled women', *Disability & Society*, 11: 1, 121-127

Rogers, C. (2009) '(S)excerpts from a Life Told: Sex, Gender and Learning Disability', *Sexualities*, 12: 3, 270–288

Rohleder, P., Swartz, L., Kalichman, S., And Simbayi, L. (2009). *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*. New York: Springer

Rohrer, J. (2005) 'Toward a Full-Inclusion Feminism: A Feminist Deployment of Disability Analysis', *Feminist Studies*, 31: 1, 34-63

Rose, N. (1998) *In Inventing our selves: Psychology, power, and personhood*. Cambridge: Cambridge University Press

Rose, N. (2001) 'The Politics of Life Itself', *Theory, Culture and Society* 18: 6, 1-30

Roulstone, A., Thomas, P. And Balderston, S. (2011) 'Between hate and vulnerability: unpacking the British criminal justice system's construction of disablist hate crime', *Disability & Society*, 26: 3, 351-364

Rubin, G. (1975) The traffic in women: notes on the 'political economy' of sex. In R. Reiter (ed) *Toward an Anthropology of Women*. New York: Monthly Review Press

Ryan, G.W. and Bernard, H.R. (2003) 'Techniques to Identify Themes', *Field Methods*, 15, 85-109

Sabo, D. And Gordon, D. (1995) *Men's Health and Illness*. London: Sage

Sakellariou, D. (2006) 'If not the Disability, then what? Barriers to Reclaiming Sexuality Following Spinal Cord Injury', *Sexuality and Disability*, 24, 101-111

Sakelliariou, D. and Algado, S.A. (2006) ‘Sexuality and Disability: a Case of Occupational Injustice’, *British Journal of Occupational Therapy*, 69: 2, 69-76

Sakellariou, D., and Sawada, Y. (2006) ‘Sexuality after spinal cord injury: the Greek male’s perspective’, *American Journal of Occupational Therapy*, 60, 311-319

Samuels, E. (2002) ‘Judith Butler's Body Theory and the Question of Disability’, *NWSA Journal*, 14: 3, 58-76

Sandahl, C. (2003) ‘Queering the Crip or Cripping the Queer? Intersections of Queer and Crip identities in Solo Autobiographical Performance’, *GLQ: A Journal of Lesbian and Gay Studies*, 9:1, 25-56

Sanders, T. (2005) *Sex Work: A Risky Business*. Cullompton: Willan Publishing

Sanders, T. (2007) 'The politics of sexual citizenship: commercial sex and disability', *Disability & Society*, 22:5, 439-455

Sanders, T. (2008) *Paying for Pleasure: Men Who Buy Sex*. USA and Cullompton: Willan Publishing

Sanders, T. (2010) ‘Sexual Citizenship, Sexual Facilitation and the Right to Pleasure’. In. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Sandoval, C. (1991) ‘U.S. Third World Feminism: The Theory and Method of

Oppositional Consciousness in the Postmodern World’, *Genders*, 10, 1-24

Scarry, E. (1985) *The Body in Pain*. Oxford: Oxford University Press

Scherrer, K.S. (2008) ‘Coming to an Asexual Identity: Negotiating Identity, Negotiating Desire’, *Sexualities*, 1: 5, 621–641

Schriempft, A. (2001) ‘(Re)fusing the Amputated Body: An Interactionist Bridge for Feminism and Disability’, *Hypatia*, 16: 4, 53-79

Sexual Freedom Coalition (2008) ‘*Sexual Freedom Coalition’*. Online. Available from: http://www.sfc.org.uk/about-2/ [accessed 4/12/11]

Sexual Health and Disability Alliance (2011) *Sexual Health and Disability Alliance*. Online. Available from: http://www.shada.org.uk/ [accessed 1/12/11]

Sexual Offences (Amendment) Act 2000 (c.44). UK: The Stationery Office Limited

Sexual Offences (Amendment) Act 2003 (c. 42) UK: The Stationery Office Limited

Seymour, J. (1994) ‘”*It’s different from being loving”: disablement, caring and marriage*, BSA Conference paper

Shakespeare, T. (1994) ‘Cultural representation of disabled people: dustbins for disavowal?’ *Disability & Society*, 9: 3, 283–299

Shakespeare, T. (1996) ‘Power and Prejudice: Issues of gender, sexuality and disability’ In L. Barton (ed) *Disability and Society: Emerging Issues and Insights*. Harlow: Longman

Shakespeare, T., Gillespie-Sells, K., Davies, D., (1996) *Untold Desires: The Sexual Politics of Disability*. London and New York: Cassell

Shakespeare, T. (1997) ‘Researching Disabled Sexuality’. In. C. Barnes and G. Mercer. (eds) *Doing Disability Research.* Leeds: The Disability Press

Shakespeare, T. (1998) *The Disability Reader: Social Science Perspectives*. London: Continuum

Shakespeare, T. (1999) ‘The sexual politics of disabled masculinity’, *Sex and Disability*, 17, 53-64

Shakespeare, T. (1999) ‘‘Losing the plot’? Medical and activist discourses of contemporary genetics and disability’, *Sociology of Health and Illness*, 21: 5, 669-688

Shakespeare, T. (2000) ‘Disabled Sexuality: Toward Rights and Recognition’, *Sexuality and Disability, 18: 3, 159-166*

Shakespeare, T. (2001) ‘Cultural Representation of Disabled People: Dustbins for Disavowal?’, *Disability and Society*, 9:3, 283-299

Shakespeare, T. and Corker, M. (2002) *Disability/Post-modernity: Embodying Disability Theory.* London: Continuum

Shakespeare, T. and Watson, N. (1995) *Habeamus corpus? Disability studies and the issue of impairment.* Paper presented at Quincentennial Conference, University of Aberdeen.

Shakespeare, T. & Watson, N. (1997) ‘Defending The Social Model’, *Disability and Society*, 12, 2, 293-300

Shakespeare T. and Watson, N. (2001) ‘Making the difference: disability, politics and recognition’. In: G, Albrecht, K. Seelman, and M. Bury (eds) *The handbook of disability studies*. Thousand Oaks, CA: Sage.

Shakespeare, T. and Watson, N. (2002) ‘The social model of disability: an outdated ideology?’ *Research in Social Science and Disability’*, 2, 9-28

Shapiro, L. (2002) ‘Incorporating Sexual Surrogacy into The Ontario Direct Funding Program’, *Disability Studies Quarterly*, 22: 4, 72-81

Sharma, U. and Black, P. (2001) ‘Look Good, Feel Better: Beauty Therapy as Emotional Labour’, *Sociology*, 35: 4, 913-931

Sharp, K. and Earle, S. (2003) ‘Cyberpunters and cyberwhores: prostitution on the internet’. In Y. Jewkes (ed) *Dot.Cons: Crime, Deviance And Identity On The Internet*. Cullompton, UK: Willan

Shaw, B. (1994) *The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag*. Louisville, KY: Avacado Press

Shearer, A. (1980) Handicapped children in residential care: a study of policy failure. London: Bedford Square Press

Sheldon, A. et al. (2007) 'Disability Rights and Wrongs?', *Disability & Society*, 22:2, 209- 234

Sherry, M. (2004) 'Overlaps and contradictions between queer theory and disability studies', *Disability & Society*, 19:7, 769-783

Shildrick, M. (2002) *Embodying the Monster: Encounters with the Vulnerable Self*. London: Sage.

Shildrick, M. (2007a) ‘Dangerous Discourse: Anxiety, desire and disability,’ *Studies in Gender and Sexuality*, 8: 3, 221-244

Shildrick, M. (2007) Contested Pleasures: The Sociopolitical Economy of Disability and Sexuality’, *Sexuality Research and Social Policy: Journal of NSRC*, 3: 3, 51-75

Shildrick, M. (2009) *Dangerous Discourse of Disability, Subjectivity and Sexuality*. New York: Palgrave Macmillan

Shildrick, M. and Price, J. (1996) ‘Breaking the boundaries of the broken body: Mastery, materiality and ME’, *Body and Society*, 2: 4, 93–113.

Shilling, C. (2003) *The Body and Social Theory 2nd Edition*. London, Thousand Oaks, New Delhi: Sage Publications

Shue, K.L. and Flores, A. (2002) ‘Whose Sex is it Anyway?: Freedom of Exploration and Expression of Sexuality of an Individual Living with Brain Injury in a Supported Independent Living Environment’, *Disability Studies Quarterly*, 22: 4, 59-72

Shuttleworth, R. (2000) ‘The Search for Sexual Intimacy for Men with Cerebral Palsy’, *Sexuality and Disability*, 18: 4, 263-282

Shuttleworth, R. (2002) ‘Dufusing the Adverse Context of Dsability and Desirability as a Practice of the Self for Men with Cerebral Palsy’. In Corker, M. And Shakespeare, T. (eds) *Disability/Postmodernity: Embodying Disability Theory*. London: Continuum

Shuttleworth, R. (2010) ‘Towards an Inclusive Disability and Sexuality Research Agenda’, In R. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Shuttleworth, R. and Sanders, T. (2010) (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Shuttleworth, R. and Sanders, T. (2010) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Siebers, T. (2001) ‘Disability in Theory: From Social Constructionism to the New Realism of the Body’, *American Literary History*, 13: 4, 737-754

Siebers, T. (2008) *Disability Theory*. USA: University of Michigan Press

Sinecka, J. (2008) "I am bodied'. 'I am sexual'. 'I am human'. Experiencing deafness and gayness: a story of a young man', *Disability & Society*, 23:5, 475-484

Smart, C. (1992) ‘The Woman of Legal Discourse’, *Social Legal Studies*, 1, 29-44

Smith, P. (1992) *The Emotional Labour of Nursing*. London: Macmillan

Smith, B. and Sparkes, A.C. (2002) ‘Sport, spinal cord injuries, embodied masculinities, and narrative identity dilemmas’, *Men and Masculinities*, 4: 3, 258-285

Smith, B. and Sparkes, A.C. (2002) ‘Men, sport, spinal cord injury and narrative time’, *Qualitative Research*, 3: 3, 295-320

Smith-Rainey (2010) *Love, Sex, and Disability: The Pleasures of Care*. USA: Lynne Rienner Publishers

Smyth, C. (1992) *Lesbians Talk Queer Notions*. London: Scarlett Press

Smyth, L. (2009) ‘Intimate Citizenship and the Right to Care: the case of breastfeeding’. In E. H. Oleksy (ed) *Intimate Citizenships: Gender, Sexualities, Politics*. London: Routledge

Sobsey, D. and Varnhagen, C. (1989) ‘Sexual Abuse and Exploitation of People with Disabilities: Toward Prevention and Treatment’, In M. Csapo and L. Gougen (eds.) Special Education Across Canada: Challenges for the 90's. Vancouver, *Centre for Human Development and Research*, 199-218

Sobsey, D. (1994) *Violence and abuse in the lives of people with disabilities: the end of silent acceptance?* Maryland: Paul H. Publishing Company

Söder, M. (1984) *Economic and Industrial Democracy*. London: Sage Publications

Solomon, Y., Warin, J., Lewis, C. And Langford, W. (2002) ‘Intimate Talk between

Parents and their Teenage Children: Democratic Openness or Covert Control', *Sociology*, 36: 4, 965-83

Solvang, P. (2007) 'The Amputee Body Desired: Beauty Destabilized? Disability Re-valued?', *Sexuality and Disability*, 25, 51-64

Soothill, K., & Sanders, T. (2005) 'The geographical mobility, preferences and pleasures of prolific punters: A demonstration study of the activities of prostitutes' clients', *Sociological Research Online*, 10: 1

Stacey, C.L. (2005) 'Finding dignity in dirty work: the constraints and rewards of low-wage home care labour', *Sociology of Health and Illness*, 27: 6, 831-854

Stein, J. (2010) 'The Sex Factor', *Target MD Spring Issue*, London: Muscular Dystrophy Campaign

Steptoe, L., Lindsay, W.R., Forrest, D. and Power, M.J. (2006) 'Quality of life and relationships in sex offenders with intellectual disability', *Journal of Intellectual and Developmental Disability*, 31, 13-19

Stevens, B. (2010) 'Crip Sexuality: Sk(r)ewed Media Representation' In R. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

Stone, E. and Priestley, M. (1996) 'Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers', *The British Journal of Sociology*, 47: 4, 699-716

Strazdin, L. (2000) 'Integrating emotions: Multiple role measurement of emotional work', *Australian Journal of Psychology*, 52: 1, 41-50

Swain, J., et al. (1993) *Disabling Barriers: Enabling Environments*. London: Sage.

Swain, J. (1996) ''Just When You Think You Got It All Sorted …': Parental Dilemmas in Relation to the Developing Sexuality of Young Profoundly Disabled People', *Journal of Learning Disabilities*, 24: 2, 58-64

Swain, J. (2004) *Disabling Barriers, Enabling Environments*. London: Sage Publications Ltd

Swain J. and French S. (2004) 'Disability and Communication: listening is not enough'. In S. Barrett, C. Komarony, M. Robb And A. Rogers (eds.) *Communication, Relationships and Care: a Reader*. London: Routledge

Taleporos, G. (2001) 'Sexuality and Physical Disability'. In E. Wood (ed) *Sexual Positions: An Australian View*. Melbourne: Hill of Content Publishing

Taleporos G. and McCabe, M. (2001) ‘The impact of physical disability on body esteem’. *Sexuality and Disability,* 19, 293-308

Teleporos G. and McCabe, M. (2002a) ‘Development and validation of the physical disability sexual and body esteem scale’. *Sexuality and Disability,* 20, 159-176

Tamm, M. and Prellwitz, M. (1999) ‘‘If I had a friend in a wheelchair’: children’s thoughts on disabilities’, *Child: Care, Health and Development,* 27: 3, 223-240

Taylor, J. (2009) ‘Cast Offs: The Verdict’, *The Independent*. Online. Available from: www.independent.co.uk/cast-offs-the-verdict-1826442.html [Accessed 24/9/2011]

Tennille, J. et al (2009) ‘Elicitation of Cognitions Related to HIV Risk Behaviors in Persons with Mental Illnesses: Implications for Prevention’, *Psychiatric Rehabilitation Journal,* 33: 1, 32 - 37

Tepper, M.S. (1999) ‘Letting go of restricted notions of manhood: Male sexuality, disability and chronic illness’, *Sexuality and Disability,* 17: 1, 37-52

Tepper, M.S. (2000) ‘Sexuality and Disability: The missing discourse of pleasure’, *Sexuality and Disability,* 18: 4, 283-290

Tepper, M. (2002) ‘Forbidden Wedding: Movie Review’, *Disability Studies Quarterly,* 22: 4, 162-164

The Outsiders (2011) ‘*Free Speech Campaign 2009’*. Online. Available from: http://www.outsiders.org.uk/node/94 [accessed 23/11/11]

The School of ICASA (2011) ‘*Fear of Intimacy’*. Online. Available from: http://www.icasa.co.uk/ [accessed 14/11/11]

Thiara, R. et al (2010) ‘Disabled Women and Domestic Violence: Making the Links, a National UK Study’, *Psychiatry, Psychology and Law***,** 18: 1, 117-136

Thiara, R. et al (2011) ‘Losing out on both counts: disabled women and domestic violence’, *Disability and Society,* 26: 6, 757-771

Thomas, C. (1997) ‘The baby and the bath water: disabled women and motherhood in social context’, *Sociology of Health & Illness,* 19: 5, 622-643

Thomas, C. (1998) ‘The Body and Society: impairment and disability’, paper presented at BSA Annual Conference *Making Sense of the Body*, Edinborough

Thomas, C. (1999). *Female forms: experiencing and understanding disability.* Buckingham: Open University Press.

Thomas, C. (2002) ‘Disability Theory: Key ideas, Issues and thinkers’, In. C. Barnes et al (2002) *Disability Studies Today*. Cambridge: Polity Press

Thomas, C. (2002a) ‘The Disabled Body’, in M. Evans and E. Lee (eds) *Real Bodies: A Sociological Introduction*. Hampshire: Palgrave

Thomas, C. (2006) ‘Disability and Gender: Reflections on Theory and Research’, *Scandinavian Journal of Disability Research*, 8:2-3, 177-185

Thompson, D., Clare, I.,, and Brown, H. (1994) ‘Not Such an 'Ordinary' Relationship: The role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour’ *Disability & Society*, 12: 4, 573-592

Thompson, S. A., Bryson, M. And Decastell, S. (2001) ‘Prospects for Identity Formation for Lesbian, Gay, or Bisexual Persons with Developmental Disabilities’, *International Journal of Disability, Development and Education*, 48: 1, 53-65

Throsby, K. (2011) ‘*Becoming a Channel Swimmer’*. Online. Available from: http://www2.warwick.ac.uk/fac/soc/sociology/staff/academicstaff/throsby/homepage/channelswimmer/ [accessed 6/12/11]

Throsby, K. and Gimlin, D. (2009) 'Critiquing thinness and wanting to be thin'. In R. Flood and R. Gill (eds) *Secrecy and silence in the research process: feminist reflections*. Ryan- Abingdon, Oxon ; New York, NY: Routledge

Tiefer, L. (2001) ‘A New View of Women's Sexual Problems: Why New? Why Now?’, *The Journal of Sex Research*, 38; 2, 89-96

TLC Trust (2011) ‘*Welcome to the TLC Trust’*. Online. Available from: http://www.tlc-trust.org.uk/ [accessed 27/11/11]

Touching Base (2008) *About*. Online. Available from: www.touchingbase.org.about.html [accessed 12/11/11]

Traustadóttir, R. (2006) ‘Disability and Gender: Introduction to the Special Issue’, *Scandinavian Journal of Disability Research*, 8: 2-3, 81-84

Tremain, S. (2000) ‘Queering Disabled Sexuality Studies’, *Sexuality and Disability*, 18: 4, 291-299

Tremain, S. (2002) ‘On the Subject of Impairment’. In M. Corker and T. Shakespeare (eds) *Disability/Postmodernity: Embodying Disability Theory*. London: Continuum

Tremain, S. (2005a) *Foucault and the Government of Disability*. Ann Arbor, MA: University of Michigan Press

Turk, V., and Brown, H. (1993) ‘The sexual abuse of adults with learning disabilities: Results of a two-year incidence survey’, *Mental Handicap Research*, 6: 3, 193-216

Twigg, J. (2000) *Bathing: The Body and Community Care*. London: Routledge

Ungerson, C. (1997) 'Give Them the Money: Is Cash a Route to Empowerment?', *Social Policy & Administration*, 31: 1, 45-53

Vahldieck, A. (1999) 'Uninhibited', *Nerve*. Online. Available from: www. Nerve.com/PersonalEssays/Vahldieck/uninhibited/ [accessed 31/8/11]

Vasey, S. (1995) 'The Experience of Care', in G. Hales (ed.) *Beyond Disability*. London: Sage

Vernon, A. (1996) 'A stranger in many camps: the experience of disabled Black and Ethnic minority women'. In: J. Morris (ed.) *Encounters with Strangers: Feminism and Disability*. London: The Women's Press Ltd

Vernon, A. (1999) 'The Dialectics of Multiple Identities and the Disabled People's Movement', *Disability & Society*, 14: 3, 385-398

Villanueva, M.I.M. (1997) *The Social Construction of Sexuality: Personal Meanings, Perceptions of Sexual Experience, And Females' Sexuality in Puerto Rico*. Unpublished thesis. Faculty of the Virginia Polytechnic Institute and State University

Wade, C.M. (1994) "It Ain't Exactly Sexy" In. B. Shaw (ed) *The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag*. Louisville, KY: Avacado Press

Waerness, K. (1984): 'The Rationality of Caring' In M. Söder (ed) *Economic and Industrial Democracy*. London: Sage Publications

Wainberg, M.L. et al (2007) 'Targeted ethnography as a critical step to inform cultural adaptations of HIV prevention interventions for adults with severe mental illness', *Social Science and Medicine*, 65: 2, 296-308

Warren, C.A.B., and Hackney, J. K. (2000) *Gender issues in ethnography, 2nd edition*. Thousand Oaks, CA: Sage Publications

Warwick, D. P. (1982) 'Tearoom trade: Means and end in social research'. In M. Bulmer (Ed.) *Social research ethics: An examination of the merits of covert participant observation*. London: Macmillan.

Waxman-Fiduccia B. (1991) 'Hatred: The Unacknowledged Dimension in Violence Against Disabled People', *Sexuality and Disability*, 9: 3, 187-199

Waxman-Fiduccia B. (1994) 'Up Against Eugenics: Disabled Women's Challenge to Receive Reproductive Health Services', *Sexuality and Disability*, 12: 2, 185-171

Waxman Fiduccia, B.F. (1999) 'Sexual Imagery of Physically Disabled Women: Erotic? Perverse? Sexist?', *Sexuality and Disability*, 17: 3, 277-282

Waxman-Fiduccia, B. (2000) ‘Current Issues in Sexuality and the Disability Movement’, *Sexuality and Disability*, 18: 3, 167-174

Waxman, B. F., & Finger, A. (1991). ‘The politics of sexuality, reproduction and disability’. *Sexuality Update, National Task Force on Sexuality and Disability*, 4:1, 1-3.

Wazakili, M., Mpofu, R., and Devlieger, P. (2006) ‘Experiences and Perceptions of Sexuality and HIV/AIDS among Young People with Physical Disabilities in a South African Township: a Case Study’, *Sexuality and Disability*, 24: ** 77-88

Weeks, J. (1985) *Sexuality and its Discontents: Meanings, myths and Modern Sexualities*. London: Routledge

Weeks, J. (1986) *Sexuality*. Chichester: Ellis Horwood/Tavistock Publications

Weeks, J. (1998) ‘The Sexual Citizen’, *Theory, Culture and Society*, 15: 3, 35-52

Weinberg, M. et al (1999) ‘Gendered Sex Work in the San Francisco Tenderloin’, *Archives of Sexual Behavior*, 28: 6, 503-521

Weitzer, R. (2000) *Sex For Sale*. London: Routledge

Wellings, K., Field, J., Johnson, A., and Wadsworth, J. (1994) *Sexual behaviour in Britain*. London: Penguin

Welner, S. (1999) ‘Contraceptive Choices for Women with Disabilities’, *Sexuality and Disability*, 17: 3, 209-214

Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge and Kegan Paul

Whipple, B. et al. (1996) ‘Sexual Response in Women with Complete Spinal Cord Injury’, In D.M. Krotoski, M.A. Nosek, and M.A. Turk (eds) *Women with Physical Disabilities: Achieving and Maintaining Health and Well-being*. Baltimore, MD: Paul H. Brooks

Whitney, C. (2006) ‘Intersections in Identity–Identity Development among Queer Women with Disabilities’, *Sexuality and Disability*, 24: 1, 39-52

Whyte, A. (2000) ‘How should nurses respond to patients’ sexual needs?’ *Nursing Times*, 96, 35

Wilchins, R. (2004) *Queer Theory, Gender Theory*. Los Angeles: Alyson Books

Wilkerson, A. (2002) ‘Disability, sex radicalism and political agency’, *NSWA Journal*, 14:3, 33–57

Williams, S.J. (1999) ‘Is anybody there? Critical Realism, chronic illness and the disability debate’, *Sociology of Health and Illness*, 21: 6, 797-819

Williams M.J., Levy Paluck, E. and Spencer-Rodgers, J. (2010) ‘The Masculinity Of Money: Automatic Stereotypes Predict Gender Differences In Estimated Salaries’, *Psychology of Women Quarterly*, 34, 7–20.

Wilton, R. and Schuer, S. (2006) ‘Towards socio-spatial inclusion? Disabled people, neoliberalism and the contemporary labour market’, *Area*, 38.2, 186–195

Whitaker, D.S. & Archer, L. (1994) ‘Partnership research and its contributions to learning and to team-building’, *Social Work Education*, 13: 3, 39-60

Wolbring, G. (2008) ‘The Politics of Ableism’, *Development*, 51, 252-258

Wolfe, P.S. (1997) ‘The Influence of Personal Values on Issues of Sexuality and Disability’, *Sexuality and Disability*, 15: 2, 69-90

Wolkowitz, C. (2006) *Bodies at Work*. London, Thousand Oaks, New Delhi: Sage Publications

Women’s Aid website (2011) ‘Topic: Sexual Violence’. Online. Available from: http://www.womensaid.org.uk/domestic_violence_topic.asp?section=000100010022 0022&sectionTitle=Sexual+violence [accessed 28.02.2011]

Women’s Aid website (2011) ‘Topic: Emotional Abuse. Online. Available from: http://www.womensaid.org.uk/domestic_violence_topic.asp?section=000100010022 0042&sectionTitle=Emotional+abuse [accessed 28.02.2011]

Wong, A. (2000) ‘The Work of Disabled Women Seeking Reproductive Health Care’, *Sexuality and Disability*, 18: 4, 301-306

Wood (2001) *Sexual Positions: An Australian View*. Melbourne: Hill of Content Publishing

Woodin, S.L. (2006) *Social Relationships and Disabled People: the impact of direct payments*. Unpublished PhD thesis: University of Leeds

Wotten, R. and Isbister, S. (2010) ‘A Sex Worker Perspective on Working with Clients with a Disability and the Development of Touching Base Inc.’, In R. Shuttleworth and T. Sanders (eds) *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press

World Health Organisation (2002) ‘*Gender and Reproductive Rights: World Health Organisation*’. Online. Available from: www.who.int/reproductive-health/gender/sexualhealth.html [accessed 23/9/11]

Wouters, C. (1989) ‘The Sociology of Emotions and Flights Attendants: Hochschild’s Managed Heart’, *Theory, Culture and Society*, 6, 95-123

Wright, E.R. et al (2007) ‘Stigma and the Sexual Isolation of People with Serious Mental Illness’, *Social Problems*, 54: 1, 78-98

Yacoub, E., and Hall, I. (2009) ‘The sexual lives of men with mild learning disability: a qualitative study’, *British Journal of Learning Disabilities*, 37, 5–11

Yoshida, K.K., Li, A., and Odette, M.S.W. (1999) ‘Cross-Cultural Views of Disability and Sexuality: Experiences of a Group of Ethno-Racial Women with Physical Disabilities’, *Sexuality and Disability*, 17: 4, 321-337

Young, M.E., Nosek, M.A., Howland, C., And Chanpong, G. (1997) ‘Prevalence of abuse of women with physical disabilities’. *Archives of Physical Medicine and Rehabilitation*, 78, 34- 38

Zarb, G. (1992) On the road to Damascus: first steps towards changing the relations of disability research production, *Disability, Handicap & Society*, 7: 2, 125-138.

Zarb, G. (1997) ‘Researching Disabling Barriers’. In C. Barnes and G. Mercer (eds). *Doing Disability Research*. Leeds: The Disability Press

Zavirsek, D. (2002) ‘Pictures and silences: memories of sexual abuse of disabled people’, *International Journal of social Welfare*, 11, 270-285

Zelizer, V.A. (1989) ‘The Social Meaning of Money: "Special Monies"’, *The American Journal of Sociology*, 95: 2, 342-377