

**SEX AND DISABILITY:
Politics, Identity and Access**

Edited by

Russell Shuttleworth and Teela Sanders

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The Disability Press

The Disability Press aims to provide an alternative outlet for work in the field of disability studies. The Disability Press draws inspiration from the work of all those countless disabled individuals and their allies who have, over the years, struggled to put this particular issue onto the political agenda. Its establishment is a testament to the growing recognition of 'disability' as an equal opportunities and human rights issue within the social sciences.

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Preface

This book represents one strategy to develop a more inclusive model of sexuality and disability research. It does so by recognising the importance for disabled people of a diversity of issues and the usefulness of employing a range of methodological approaches in their investigation. Following a review of the sexuality and disability research literature in which many issues and perspectives were found lacking, two international conference symposia were organised around the theme of an inclusive sexuality and disability research agenda and a paper was presented on this theme at another international conference. Funding for the review of literature, organisation of symposia and attendance at these conferences was provided by an International Program Development Fund Award with matching funds provided by the Faculty of Health Sciences, University of Sydney. The general purpose of these funds was to promote international collaboration between universities in the World University Network. My co-editor, Teela Sanders from the University of Leeds, was an international collaborator on this award. The editors organised sexuality and disability symposia entitled, Towards an Inclusive Sexuality and Disability Research Agenda at both the 2008 Disability Studies Association Meeting held at Lancaster University in the United Kingdom and the 2008 Society for the Scientific Study of Sexuality held in San Juan, Puerto Rico. Many of the chapters in this volume were presented at these two symposia in which we specifically wanted to highlight issues and perspectives that are for the most part being overlooked by sexuality and disability researchers. We also contacted several other researchers working on marginalised topics and solicited chapters from them.

Another important impetus for this edited book has been the extraordinary group of postgraduate research students in the Graduate Program in Sexual Health, Faculty of Health Sciences, University of Sydney. Several of these students are beginning to investigate issues that have been neglected in sexuality and disability research. I feel privileged to be part of this pioneering effort and involved in their research supervision. A couple of these students have also contributed to this edited volume.

Aside from providing feedback to authors on clarity of meaning and grammar through a couple of drafts, the editors have made no effort to influence the particular language, style or arguments of the authors. While at times this may appear to diminish the book's cohesiveness, the editors nevertheless feel it is important to grant authors creative autonomy within the parameters of the volume's agenda. In an era when editors are seemingly dictating the precise style and in fact often the terminology that should be incorporated into a text, we believe the broad principle of inclusion is best served by a more flexible approach. This of course does not mean that we tolerated (dis)ableist, sexist, heterosexist, racist, etc. language. The issue we are discussing here has more to do with disciplinary, epistemological and conceptual boundaries imposed on contributors by the particular approach of the editor(s).

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CHAPTER 1

Towards an Inclusive Sexuality and Disability Research Agenda

Russell Shuttleworth

Accessible Summary

Much of the research on disabled people's sexual lives is about: 1) how well their genitals work; 2) whether disabled people feel as positive about their bodies or sexual lives as non-disabled people; 3) how their sexual lives and relationships compare to non-disabled people's sex lives; and 4) how disabled people adjust sexually when they become impaired. While this research can be useful, many important everyday issues that disabled people bring up when talking about their sexual lives have not been looked at very much. In addition there are many other gaps in what we know about sexuality and disability. Below are some of the major gaps in the research:

- Several issues concerning disabled people's sex lives remain under researched because they often make people uncomfortable—such as personal assistants or other care providers helping disabled people in some practical way to express themselves sexually (for example, buying condoms for a client, positioning a client so they can masturbate or have sex with another disabled person). Another example of an under researched area is the issue of some disabled people (mostly men) accessing or wanting to access sex worker services and the barriers they face.
- There has also been little research in non-Western societies on disabled people's sexual issues and the barriers that they sometimes face in trying to lead enjoyable and meaningful sexual lives.
- When researchers plan research on sexuality and disability, disabled people are often not asked what the important issues are for them and/or not included as co-researchers in some way.
- There have been only a few different lenses through which researchers have looked at disabled people's sexual lives in their studies. A researcher's theoretical lens is the way that a particular researcher looks at and explains a particular problem. Looking at disabled people's sexual lives through different lenses is similar to looking at a person from different places around her or him: Each time we get a different view of the person but it is still the same person. We need to look at disabled people's sexual lives from different places to understand the different sides to the issues that disabled people face in this area.

Introduction

The publication of *The Sexual Politics of Disability* by Tom Shakespeare, Kath Gillespie-Sells, and Dominic Davies (1996), a landmark study of disabled people's sexuality in the United Kingdom, appeared to signal a coming of age for inclusive research in this area. The first large scale study that documented a range of sexual concerns for disabled people with a variety of impairments and that significantly relied on disabled people's own voices in the final text,

this work suggested a focus on a broader range of sexuality and disability issues than those that had been traditionally emphasized in the largely medical approach which had predominated (Gill 1989, Hahn 1981). Especially noted were the sexual implications of the intersection of disability with identity categories such as gender, race and sexuality, as well as complex moral or ethical issues such as disabled people's use of sex worker services and facilitated sex. At the time, these researchers chose to provide minimal theoretical elucidation—referencing the social model of disability and briefly discussing the concept of sexual citizenship. While Shakespeare's later writings on sexuality and disability (eg 1999b, 2000, 2003) suggest inclusion of other disciplinary and conceptual perspectives (e.g. feminism, queer studies), he and his colleagues initial atheoretical emphasis can be viewed as an important emancipatory move to shake off the oppressiveness of researcher-designed and functionally-oriented approaches. Despite the lack of theory, Shakespeare, Gillespie-Sells and Davies break from tradition had the potential to significantly influence a broadening of the sexuality and disability research agenda both empirically and conceptually. Yet, a partial review of the sexuality and disability research literature from 1997-2007, searching the databases Anthropology Plus, Proquest 5000, Web of Science via ISI Web of Knowledge, Medline, Cinahl and PsycInfo, shows that while sexuality and disability research during this ten year period was somewhat more inclusive of a wider range of issues and perspectives than in 1996, the promise of their work appears to have only partially been realized (Shuttleworth 2007b, unpublished).

Sexuality and disability research still tends to be dominated by approaches that 1) perceive disabled people's sexuality as a problem to be solved at the level of the individual; 2) are explicitly or implicitly concerned with treatment objectives; 3) focus on how individuals stack up on a scale of sexual functioning; and 4) view the issue of disabled sex in terms of physiological, psychological, social and relational norms derived from research with non-disabled people. This kind of work would include any studies in which a major research objective is to measure the interaction of variables in terms of sexual and/or relational normality (eg genital function, body image and sexual self esteem, sexual activity both within and outside intimate relationships and satisfaction/dissatisfaction and sexual knowledge and attitudes). Individual adjustment to one's impairment in relation to normative sexuality is often the purpose of much of this work. Much less investigated are the sociopolitical 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 sexuality and disability issues, and other topics less concerned with normative functioning. Not surprisingly those methodological approaches that employ quantitative approaches utilising questionnaires and surveys are favored over approaches that employ qualitative research methods such as interviews and participant-observation. When qualitative methods are employed a positivist methodology is still preferred, in which social reality is naively viewed as self-evident, over critical and hermeneutic

perspectives in which meaning is interpreted and negotiated (Shuttleworth unpublished).

It is not my intention to disparage sexuality and disability research concerned with function and individual adjustment or those studies that employ quantitative methodologies. Such work has assisted many disabled people in leading fulfilling sexual lives. The purpose herein is simply to broaden the sexuality and disability research agenda to include those issues and perspectives that have been given short shrift. Interestingly, the focus on sexual functioning rarely includes detailed description 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 (Hamam, McCluskey and Shuttleworth 2009). I would emphasize that a focus on function is especially imperative at particular moments in many disabled people's lives. For example, rehabilitation is crucial for those persons who experience a spinal cord injury as they learn how to function, adapt and accommodate to their new physiological condition. Addressing sexual concerns is also paramount during this time, and as many researchers have argued, should be a crucial aspect in the rehabilitation process (Tepper 1997). Thus, rehabilitation research on sexuality and intimacy for people with a range of impairments must remain an important concern. Then too, a research focus on functioning does not always result in findings that simply reinforce sexual norms. For example, some research with spinal cord injured people describes their loss of genital sensation and subsequent erotic investment in areas of the body that have retained sensory feeling (see for example Whipple, Richards, Tepper and Komisaruk 1996), which shows them actually reconfiguring their relation to normative sexual functioning; this complicates the neat categorisation of research issues and methodologies. Recognizing the value of the predominant lines of study, however, should not obscure the fact that there is still a marked lack of innovative sociopolitical and cultural research in sexuality and disability—work that critically analyses social practices, public policies and cultural meanings and evaluates their impact on disabled people's sexual lives.

The Sexual Politics of Disability

The disparity that exists between the kinds of issues studied in sexuality and disability research needs to be acknowledged and openly discussed. Perhaps the most egregious lack is in regard to those issues which raise ethical, moral, practice and/or policy dilemmas such as some disabled people's need for facilitated sex or their use of sex worker services. The controversial nature of, for example, personal assistants helping to facilitate disabled people's sexual expression or their sexual encounters should be the cue for sexuality and disability researchers to shine a beacon on this issue. While an individual's physical functioning obviously plays a role here, that is, their difficulty in meeting their own sexual expression needs, the ethical dilemmas surrounding and political and structural barriers to implementing sexual facilitation services constitute the primary aspects that have been neglected in research (see Shildrick 2007, Shuttleworth 2007a, Shuttleworth and Mona 2002). However, those who attempt to research such issues can encounter resistance from multiple sources including funding mechanisms, ethics committees, traditional

disciplines and even some disabled people themselves (see, however, Bonnie 2002, J Brown and Russell 2005, Earle 1999, 2001).

For example, I have heard from several researchers in the United States that their efforts to research facilitated sex and disability have encountered resistance from foundations who fund disability research and also Independent Living Centers. One researcher told me that a disabled employee of the latter said to her, "We have more important issues to deal with!" I myself have encountered a lack of interest from quite a few academic faculty members within Australia who have the track record necessary to pitch a proposal for funding to government funding schemes. These conservative schemes for the most part have a stranglehold on what issues and perspectives will obtain funding. Thus, the vast majority of researchers choose to ignore controversial topics and study more traditional and thus fundable types of research.

However, sociopolitical research that especially takes account of how local policies can impact on disabled people's sexual lives is imperative (Abbot and Burns 2007, Shildrick 2004, Shuttleworth 2007b). Policy contexts relating to particular issues vary widely even among Western societies. For example, consider the vastly different policies concerning sex work and how this can affect disabled people's sexual access. Working as a personal assistant for disabled men for many years in the San Francisco Bay Area, I occasionally heard talk of some men's visits to sex workers, which was usually conveyed in hushed tones. This issue was not allowed to reach the level of public discourse because of the illegality of sex work in California. I occasionally facilitated access to sex workers for one of the disabled men who employed me and the risk involved in the situation was certainly palpable to us in terms of the often difficult process of making and maintaining reliable contacts among sex workers and their anxiety about being arrested (Shuttleworth 2000). In Sydney, Australia where I currently reside, sex work is decriminalized and the discourse around disabled people's access to sex worker services is public, with sex workers, disability organizations, social critics and disabled people all contributing their perspectives to the discussion. While there are still barriers to disabled people accessing sex worker services, these impediments are programmatic, attitudinal and architectural and not related to the legality of the service.

Yet the continuing existence of non-legal kinds of barriers for disabled people even in such sexually progressive regions as several Australian states shows the multidimensionality that can exist regarding the larger policy context of sexuality and disability. In fact, not all scholars are so positive about the increased public visibility and increasing acceptance of disabled people using sex worker services. Sheila Jeffreys (2008) argues that access to sex workers is occurring via disability charities and services who promote the male sex right on the grounds of the sex rights of disabled people; the gender neutral language being simply a screen for getting disabled men's sex needs met. Her argument is linked to the larger issue of male dominance and its reflection within the disability sector, especially within rehabilitation programs that she claims "are about 'enabling men to aspire to dominance notions of masculinity' whilst ignoring the needs of disabled women" (2008: 327). Jeffreys' perspective, however, contrasts with a recent literature review in which an important finding was that from 2001 through 2007 the number of

studies on disabled women's sexuality, many of them from a rehabilitation perspective, equalled or exceeded research on disabled men's sexuality (Shuttleworth unpublished).

Jeffrey argues further that:

the male sex right...leads to the provision of prostituted women to men with disabilities, the provision of what are euphemistically called 'sex surrogates', or even the requirements that nurses and carers masturbate men with disabilities, which is called 'facilitated sex' (2008: 328).

The professionalization and legitimacy of sexual surrogacy has grown significantly since the personal essay she cites as her primary reference point on this topic was written (see O'Brien 1990). Used in conjunction with the required sex therapy, sexual surrogacy is 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. Jeffrey's implication that facilitated sex is primarily concerned with masturbating disabled men is also inaccurate and inconsistent with her own definition of this service earlier in her article. In fact, there are a wide range of activities that constitute facilitated sex of which both men and women can benefit from. Jeffreys, however, is correct in her assertion that disabled men are the primary customers for sex worker services. Yet, this may simply reflect how the construction of female gender roles constrains disabled women sexually (see Hamilton this volume) and should be a call for systematic research to more fully apprehend 1) what are in fact disabled women's sexual and intimacy needs; and 2) how they might better be addressed.

Whilst Jeffrey critiques the sex industry for exploiting disabled people (2008: 332), two sex workers in Sydney, Rachel Wotten and Saul Isbister, in their joint chapter describe how a perception of the need to assist disabled people and sex workers in connecting with each other resulted in their founding of the organization, Touching Base. Wotten and Isbister further present some of their experiences and insights in working with disabled clients. As insiders committed to breaking down the barriers to sex worker services that exist for disabled people in New South Wales, they present a picture of concern in contrast to exploitation. Wotten and Isbister describe how they eventually reached the decision to conduct two complementary research projects: one with disabled people on their perception of the barriers to accessing sex worker services and another with sex workers on their perception of barriers.

Teela Sanders' chapter shows the complexities involved in the use of sex worker services by disabled people. Maintaining that these services should only be seen as one option for disabled people (see also Griffiths 2006), Sanders examines this issue in conjunction with facilitated sex. She employs a broad sexual rights framework in order to investigate a range of political concerns that surround these issues. Sanders critically discusses the different legal and policy frameworks internationally that impact on disabled people's rights to a sex life. Exploring the relationship between sex work lobby groups and activists with the disabled rights movement, she suggests that

there needs to be more allegiance between these groups for better outcomes for both sex worker labour rights and the rights of disabled people to purchase sex and express their sexuality. Sanders concludes that sexual consent and freedom for all should be protected in order that sexual diversity be disentangled from deviancy and criminality.

Sexuality and Disability in Non-Western Societies

There is a significant lack of cross-cultural research on sexuality and disability in non-Western societies. From 1997-2007 there was only a slight increase in research conducted in non-Western societies; 90 per cent of research is still conducted in Western societies such as the US, UK and Canada (Shuttleworth unpublished). Those studies that do report information mostly focus on disabled people's opportunities for marriage in particular societies, which while often relevant to sexual lives cannot be considered equivalent to them (eg Fassin 1991, Nicolaisen 1995). Qualitative research attention should especially be drawn to the higher rates of STDs including HIV/AIDS in both developed but especially developing countries (Groce 2004, 2005) to enable us to understand the context, meaning and lived implications of these higher figures. Despite the limited cross-cultural research, there is growing evidence that just as in the the West, disabled people's sexuality is devalued in many non-Western societies; the sexual lives of people with various impairments interacting with social institutions such as gender, marriage, class, etc. may be restricted in various ways (Shuttleworth 2004a)

Recently Ingstad (2007) has problematised the concept of universal human rights and the agenda of the disability rights movement. She argues that cross-cultural researchers must take into account perspectives within the local context rather than assume universal standards for human rights in relation to disabled people. One of her main points is that in the developing world where there is often rampant poverty, concepts such as independent living and accommodations for disabled people that are taken for granted in some Western societies such as wheelchairs may not be relevant or at least less immediately important than a more basic concern with the family's economic survival. She further cautions us not to impose forms of individualism onto the interpersonal relations of disabled people and non-disabled people in societies in which the response to disability may be more familial and communal. In one of her illustrations of this point, taken from her own research in Botswana, the rape of women with learning disability can sometimes be viewed by family members as insurance that they will be cared for in later life. This is a complex issue and Ingstad provides a detailed description of the impoverished circumstances that can figure into this perception. Another example she uses from her own work is that a person's marital status in Botswana is not about whether they are disabled (impaired sic) or not but is dependent on their ability to provide for a family. Of course, in social model parlance, disability is the very fact that a particular society restricts access to avenues of livelihood for people with certain impairments, which might in turn restrict access to marriage. Since as Ingstad mentions many people in Botswana both disabled and non-disabled are experiencing difficulty in providing for a family, I think it would be hard to currently discern the degree to which various impairment(s) affect this ability. While she mentions that some disabled people do manage to find work, it seems that in

these impoverished circumstances the majority of disabled people experience a more basic integration into their extended family.

Given the complexities that Ingstad discusses, I would definitely agree with her that each situation must be contextualised locally. One should certainly not export a form of conceptual imperialism to non-Western societies. Yet, as I have argued elsewhere (2004a), there is a stark absence of critical perspectives in previous work within the anthropology of disability. After all, an investigation of power relations is not unusual to find in the cross-cultural study of other social categories of persons such as women or the elderly. The call for a more critical ethnographic approach was not meant to displace an understanding of the local context; they are, in fact, not mutually exclusive. Rather, incorporating an understanding of power relations into the conceptual arsenal of cross-cultural disability researchers can make us wary of uncritically perceiving that integration exists when further investigation is warranted. This is especially imperative for cross-cultural research on sexuality and disability, as sexuality is often viewed a secondary concern for researchers and policy-makers even in Western societies. In fact, Ingstad, a pioneering researcher in the anthropology of disability now advocates a middle-road ethnographic approach between the uncritical acceptance of universal human rights standards and radical relativism (Ingstad 2007), which suggests a maturing of cross-cultural research in this area.

Godfrey Kangaude (2007) has examined human rights and sexual rights for disabled people in Malawi. Kangaude provides a compelling argument that the consequence of minimising disabled people's need for sexual expression and initially leaving it off the developmental agenda in that society has meant that in policy documents and practice contexts disabled people's sexual restrictions are implied and thus in a sense codified. It subsequently becomes a struggle to counter institutional precedence. Of course, the fact that in Malawi legislation was often transplanted from English law needs to be taken into account in any discussion of human and sexual rights in that country. Kangaude's analysis sets the stage for critical empirical research on sexuality and disability in Malawi.

In the present volume, Kangaude focuses on how disabled people are perceived as asexual not only in Malawi but also many other societies. He examines the impact of this discrimination on the lives of disabled people through the concept of sexual access and highlights the complicity of social and legal frameworks in perpetuating this notion. Addressing this question on an international level, Kangaude argues that policy and legal frameworks must reflect the obligation and commitment of states to advance the sexual rights of disabled people.

In her chapter, anthropologist Sarah Phillips does justice to Ingstad's call for careful analysis of the local context. Through the narratives of two disabled men who live in the Ukraine, Phillips focuses on the intersection of disability, masculinity and sexuality. The Ukraine currently is undergoing massive economic and political transformation, but the traditional gender roles and institutional structures of the Soviet regime still exert tremendous force over an individual's behavior. In short, these restrictive structures and gender expectations present very real impediments for these men's desire for a better life. Despite the myriad of barriers, Phillips' analysis reveals that by both negotiating with and resisting hegemonic masculinities these men

pragmatically expand their masculine repertoires for their own social and sexual benefit. Additionally, her study clearly demonstrates the value that qualitative methods such as ethnography and life history interviewing can have for sexuality and disability research.

Disabled People's Participation in Research

A social justice oriented approach to research requires that our participants be included as collaborators, alerting us to pertinent issues and contributing in important ways to the formulation of sexuality and disability research. Indeed, a critical, emancipatory orientation lies at the core of disability studies' *raison d'être* (C Barnes 1992b, 2003, Mercer 2004, Oliver 1992), and disabled people's perspectives must be included in the design of research in this area. Unfortunately, disabled people's participation and collaboration in sexuality and disability research has increased only minimally since the mid-1990s (Shuttleworth unpublished). While some sexuality and disability researchers consult with their participants about what research foci are important for them and attempt to elicit their contribution, the degree of participation is often implicit. I would argue not only for increased participation by disabled people in the research design but also an explicit articulation within research reports of which aspects of the study were open to their participation.

An impairment group whose participation in research on their sexual lives has rarely been elicited is people with learning disability or learning difficulties depending on the local context. Much of the research that focuses on this group has been concerned with either sexually inappropriate behaviour and perceived tendency to sexual abuse by men experiencing this condition (Shuttleworth unpublished, N Wilson, Parmenter, Stancliffe, Shuttleworth and Parker 2010) or with the vulnerability to sexual abuse of mostly women (but also some men) with learning disability or difficulties (Shuttleworth unpublished). In her chapter Andrea Hollomotz focuses on the latter. Hollomotz draws from her experience as a social worker for adults with learning difficulties and also her participatory research with this population. She is concerned with eliciting the perspective of people with learning difficulties about their sexual abuse. Hollomotz shows how their so-called vulnerability to sexual abuse is at least partially constructed by their social environment. In short, Hollomotz argues that disempowerment and control in the lives of people with learning difficulties reinforces their sexual vulnerability.

Within the present volume, Ruth Garbutt is the most explicit about the participation of disabled people in her research. Garbutt considers some of the issues around sex and relationships for young people with learning difficulties and draws on some of the preliminary findings of an emancipatory research project looking at the issue. She employs an innovative approach that uses drama as a methodological technique to find out about the views and experiences of these young people. Garbutt also includes a national survey of special schools, interviews with parents, and focus groups with teachers and governors as data in her chapter. The findings of her study clearly show how disabled people's participation in designing and operationalising the research led to elucidation of some of the barriers they face in their sexual lives.

While all the contributors would agree that disabled people's sexual issues should be at the forefront of the research agenda and to include their

goals and ideas in the research design (C Barnes 1992b, 2003, Stone and Priestly 1996), I would warn against uncritical employment of the concepts of participation and emancipation and a demotion of the researcher's role to social technician instead of critical-interpreter (Meekosha and Shuttleworth 2009, Shakespeare 1996b). Given that disabled people themselves often hold varying views of an issue, eliciting overall consensus on the design of any research project can prove problematic (J M Davis 2000). Especially in terms of analysis, the researcher committed to social justice, whether disabled or non-disabled ally, can bring a crucial critical-interpretive understanding to the issues of marginalized groups by articulating the conceptual links between institutional structures, social processes, cultural meanings, psychoemotional dispositions and embodied feelings. Interconnections between these aspects must be illuminated in myriad ways to assist in their becoming more visible and thus amenable to change.

Theorising Sexuality and Disability

In her chapter, Carol Hamilton offers a case in point of an innovative analytical approach that goes well beyond perceiving the processes and meanings of social life as transparent. A longtime ally of people with learning disability, Hamilton is concerned with the barriers to this population's sociosexual development that still exist for workers within service agencies in New Zealand. Despite incorporating policies acknowledging that they may need to assist learning disabled people in the area of sexuality and intimacy, there is a tendency in these agencies to not seriously address issues, which often require a systematic plan of support. This is especially apparent in the lack of attention paid to issues of gender. Hamilton's critical discursive analysis of transcripts from interviews she conducted with direct support workers reveals sexually oppressive structures that are often obscured by the common sense gender assumptions operating in their discourse. Hamilton argues that gender expectations construct learning disabled men's sexual 'need' as easily recognizable and men as more sexually agentic than learning disabled women, who are viewed as powerless 'sexual victims.' However, rather than placing the blame on workers for the sexually restrictive consequences of these gendered assumptions on learning disabled women's sexual lives, she maintains that they as much as learning disabled people are "discursively shaped by the social conditions of their (sexual) lives." Hamilton concludes by encouraging us to think productively about these kind of assumptions, which underlie support work in this area.

Theoretical approaches that employ innovative conceptual frameworks such as Hamilton's, however, are still rarely utilized in sexuality and disability research. Emergent approaches that draw from the current myriad of critical social theories are often resisted by mainstream sexuality and disability researchers and some disability studies scholars who still adhere strictly to social constructionist perspectives. Yet, the limitations of a strictly social constructionist approach are being increasingly acknowledged more generally in disability studies (see for example Shakespeare 2006, Shildrick 2007, 2009). The social theorist Margrit Shildrick (2007, 2009) argues that constructionist approaches simply work through modernist dilemmas (e.g. self vs society, agency vs structure). In fact, Shildrick, who is not an empirical researcher but whose work has important implications for research on

sexuality and disability, draws from an array of perspectives including post-structuralism, phenomenology and psychoanalysis in her own theorization of sexuality and disability. The fact that the study of sexuality and disability is finally beginning to draw attention from critical social and cultural theorists outside the traditional applied disciplines and empirical social sciences is a significant development in this area (see for example McRuer 2006a, McRuer and Wilkerson 2003, Shildrick 2004, 2007, 2009, Wilkerson 2002).

Drawing ideas from an eclectic mix of theories besides social constructionism can open up important avenues of investigation. In her work (2004, Shildrick 2007, 2009), Shildrick painstakingly details how disabled people's anomalous embodiment can uncover an anxiety of the other within the self, which underscores the vulnerability of human embodiment in general. This process reaches its most acute form during sexual encounters. She argues that the psychic underpinnings of the response to anomalous embodiment has contributed to the development of adverse sociocultural contexts of disability and desirability, Shildrick, however, argues that the diverse sexual expressions of disabled people and their inter-relations with others that can sometimes ensue from anomalous embodiment (e.g. being provided assistance by a paid worker during sexual encounters, incorporating spasticity into lovemaking with a non-disabled lover), actually signifies the potential for breaking the bonds of Cartesian thinking and heteronormative sexuality in postmodern society, which will benefit not only disabled people but all excluded others and ultimately everyone. Employing more recent critical thinkers such as Irigaray, Deleuze and Guattari and Stiker, she manages to significantly flesh out the phenomenological and psychic background to the response to anomalous embodiment that Harlan Hahn had briefly flirted with in the late-1980s (Hahn 1988a, b). Shildrick's work, which I cannot do justice to in this brief glimpse, will hopefully contribute to breaking down the barriers to employing especially phenomenological and psychoanalytic approaches sensitive to sociocultural issues in disability studies and research on sexuality and disability.

Another innovative perspective is that of Abby Wilkerson (2002) who employs the concept of cultural erotophobia, an irrational reaction to eroticism which suggests a shamefulness associated with sex, to highlight some of the sexual harms that are perpetrated on disabled people. Wilkerson argues that:

oppressed groups generally tend to share the experience of being particularly subject to erotophobic judgments of their sexual behaviors or "natures," restrictions against practices associated with them, sexual violence and harassment, and other constraints on their sexuality. If sexual harms, including stereotyping, are one of the hallmarks of oppression, then cultural associations of a group with specific sexual tendencies or ways of being are (for all but the most privileged) connected to significant material and psychological harms inflicted on its members differentially. This suggests, furthermore, that erotophobia is a central tool of inequality.

Wilkerson's approach is an effective means of highlighting and drawing together a host of social hierarchies, sexuality, gender, class, race, age and ability, while also maintaining a specificity to the particular harms that are

perpetrated on each group, e.g. the sexual abuse that disabled people are often subjected to and the homophobia that queers often endure. This perspective obviously has implications for those empirical researchers who focus on intersectionality in their work (Meekosha 2006).

An important intersectional account in the present volume is Zowie Davy's chapter, which employs a critical post-modern lens to illuminate the phenomenological experiences of a transman who is disabled and identifies as queer. The participant's narrative reveals the ways in which he negotiates his gender and sexual citizenship through various sexual, social and phenomenological body images. This transman's negotiations are structured in relation to the (dis)abling effects of social institutions, such as medicine, law and family that have much of the power to grant him social legitimacy or not. An intersectional analysis of disabled, transgender and sexual identities provides nuanced explanations of how in the face of myriad institutional constraints he manages to secure a coherent identity, while dynamically negotiating these contexts with his intersectional identities. On another level, Davy's chapter can be viewed as one researcher's attempt to theorise a complex empirical case that does justice to the tendency of our research participants to continue to interpret their lived experience in modernist, dichotomous terms of self-other, autonomy-interconnectedness, and agency-constraint, but also deconstructs participants' interpretations to show the contextuality and fluidity of their identities.

Sexual access is another concept that has been employed in recent work and especially lends itself to an interrogation of the sociopolitical and cultural impediments to disabled people's sexual wellbeing (Grossman, Shuttleworth and Prinz 2004, Hamilton 2002, Kangaude 2007, O'Toole 2002, Shuttleworth 2007a, b, Shuttleworth and Mona 2002, Wade 2002). While on one level the notion is clearly inspired by social constructionism, sociopolitical models of disability and human rights discourse, the concept is not necessarily restricted to those senses. For example, in previous work I have fleshed out an existential-phenomenological sense of disabled people's everyday contention with and resistance to adverse cultural and sociosexual contexts that sheds light on the the psychoemotional development of sexual agency and fits loosely with attempts to conceptualise the impact of prejudice and oppression on disabled people's inner, psychoemotional lives (Reeve 2002, Thomas 1999, 2004). While admittedly aspects of these kinds of analyses are situated within a modernist framework, the social justice oriented, empirical researcher cannot forsake the grounding of their analyses and interpretations in the everyday struggles and resistance of research participants (Shuttleworth in-press). While there is much current discourse about how post-modern culture is transforming notions such as "the subject", the participants in our research reveal that modernism is far from dead. In other words, our research participants still often reflectively perceive themselves as autonomous agents even if prereflectively they may be more contextually sensitive and interdependent. Thus, a research programme on sexuality and disability must recognize that sexual agency and sexual relationality may currently be situated between modernist and postmodern conceptions of the self-other dynamic. From another angle, it should also be noted that anthropological discourse has a long history of contrasting cultures in which the self is viewed in more individualistic and autonomous terms

versus those cultures in which the self is viewed as more relational and interdependent; this discussion has become less dichotomous and more nuanced in the 1990s and into the new millennium (see for example Ewing 1990).

While the objectives of qualitative social and cultural research—studying the cultural meanings, social structures and interpersonal meanings and situations of people who have some aspect or issue in common—is of necessity grounded in what participants say and do, we must nevertheless also question normative categorizations within their and our own conceptual understandings. For example, a focus on sexual access need not simply interrogate disabled people's sexual restrictions in terms of normative sexual identities, relations and practices, but can aim at illuminating a more inclusive access to 'sexual wellbeing' no matter its attributes/requirements. As Brown & Russell (2005) state, sexual wellbeing is "conceptualised broadly as the capacity to enjoy and continue sexual behaviour in line with a personal and social ethic" (376). Opening the concept out in this way, links to heteronormative sexuality are severed. Of course, queers would experience forms of sexual oppression that heterosexuals do not and this aspect needs to be accounted for in any analysis. But whether disabled people's sexual wellbeing is nurtured through culturally sanctioned, heteronormative avenues (e.g. dating, marriage), atypical (e.g. communal, BDSM) and queer lifestyles or modes of relationality that emerge from their diverse socio-bodily situations (e.g. being provided personal care by a paid assistant during sexual encounters, incorporating spasticity into lovemaking) is on a comparative level irrelevant to the task of describing and elucidating sexual access in a particular case. While this formulation will likely not satisfy those who require a thorough deconstruction and dissolution of identity intersections in order to "envision a future in which there are no 'dis/abled sexualities'" (Rembis 2010: 56), it does provide a pragmatic, heuristic device for researchers to gauge the current sociosexual situations (degree of restriction or access to desired sexual contexts, identities, wellbeing, etc) of people with a range of impairments.

While many of the chapters in this volume are implicitly concerned with sexual access, several chapters explicitly focus on this notion. As mentioned, Kangaude's chapter utilises this concept in his discussion of the sexual rights of disabled people. In her chapter, also discussed above, Garbutt argues that wider political issues and social processes restricting learning disabled people can be linked to the multiple barriers to learning disabled people's sexual wellbeing and to developing intimate relationships. Craig Blyth, drawing upon his research with men who identify as both disabled and gay, similarly employs an access approach in his chapter. Blyth interrogates the multiple barriers that these men face in attempting to negotiate access to Manchester's now famous 'gay scene,' Canal Street—barriers which include 'gay obsession' with bodily perfection, youth, physical prowess and sexual imagery. Not being able to access the commercial gay scene has thus resulted in these men seeking out alternative ways of meeting other gay men for sexual relations and encounters, the primary alternative being frequenting public toilets or 'cottages'. Drawing insights from his research, Blyth critiques current trends in the discourse of disability, sexuality and masculinity for their inherent exclusions.

In her chapter, Bethany Stevens discusses the lack of sexually positive representations of disabled people in the mainstream media. Stevens painstakingly describes the role of the media in framing the sexual identity of disabled people. She argues that the media is a powerful force in determining the social value of disabled embodiment that skews the understanding of their sexuality and reifies the institution of able-bodiedness. This lack of sexually positive representation in the media can present a major impediment to accessing sexual wellbeing for many disabled people (Shuttleworth and Mona 2002). Stevens contends, however, that the media can also serve as a revolutionary tool to challenge and subvert the adverse cultural understanding of disability and disabled people's sexual lives. She concludes by discussing the resistance and subversion to their asexual representation that people exhibiting a range of bodily and psychic configurations are increasingly exhibiting via performances such as *Sins Invalid* in the San Francisco Bay Area. Thus, by seeking out alternative sociosexual contexts (Blyth's participants) and in resisting hegemonic notions of what it means to be desirable and sexual beings (*Sins Invalid* 2008), many disabled people are currently challenging the restrictive social spaces and cultural meanings that have traditionally structured their sexual access.

Conclusion

An inclusive model of sexuality and disability research recognizes the diversity of sexuality and disability issues and utility of the entire range of methodologies and conceptual frameworks, delineating their usefulness for particular cases. While in this volume preference is given to those issues and perspectives that have been traditionally neglected in research, the editors recognise that all research in this area can contribute to disabled people's sexual wellbeing. The interest that sexuality and disability is beginning to receive from critical social and cultural scholars not necessarily connected with either applied disciplines or empirical research in the social sciences is hopefully a healthy sign of progress toward disabled people's sexual wellbeing. The recent emergence of a genre of disability performance in which disabled people's resistance to and subversion of hegemonic bodily and sexual norms is given centre stage can also work towards influencing the larger cultural acceptance of disabled people as desiring and desirable sexual beings. Realistically, sociosexual change in this area will be an incremental process not a utopian leap as our conceptually and empirically rich analyses of disabled people's sexuality and sociosexual situations converge with sexual rights and disability rights activism, provocative sex and disability performances such as *Sins Invalid*, critical and innovative social and cultural theory and progressive social policies and practices to gradually change public consciousness.

PART I

CONSTRUCTING THE SEXUALITY OF DISABLED PEOPLE

CHAPTER 2

Vulnerable Adults? The Social Creation of Risk to Sexual Violence

Andrea Hollomotz

Accessible summary

Many people say that disabled people are vulnerable to sexual abuse. Vulnerable means that someone needs to be protected because they cannot protect themselves. Sexual abuse is when someone makes you do sexual things that you do not want to do. That could be:

- when someone touches you on parts of your body that are private to you;
- when someone makes you touch them on their penis, breasts or vagina;
- if someone forces you to watch sex or;
- if someone forces you to have sex with them.

This chapter asks: Are disabled people vulnerable to sexual abuse? In other words: Are they unable to protect themselves? I have made a list of things that are said to make disabled people vulnerable. Some of those are:

- not enough knowledge about sex and sexuality,
- being unable to make decisions and
- low self-esteem.

I have spoken to 29 people with learning difficulties. I wanted to find out how they are supported. Are they allowed to stand up for themselves in everyday life? I found that:

- Some people were not allowed to have positive sexual experiences. That means they cannot find out what they like about sex.
- Some have been told things about sex that are wrong.
- Some have not been told enough about sex. A person needs to know what sex is, so that they can understand sexual abuse, too.
- Some people were not allowed to make their own choices. Other people made choices for them. If a person cannot make choices about simpler things, like what to eat, they will find it difficult to make choices about hard things, for example if they would like to have sex or not.
- Some people have been disadvantaged because they are disabled. This led them to believe that being disabled is a bad thing. They had low self-esteem. If a person does not feel confident, they will not stick up for themselves.

Disabled people are not supported well enough. They become less able to protect themselves from sexual abuse because of how we treat them. We do not give them enough opportunities to learn the skills that would make them less vulnerable.

Introduction

Geographers conceptualise 'vulnerability' as a relationship that humans have with their environments, which focuses:

attention on the totality of relationships in a given social situation which constitute a condition that, in combination with environmental forces, produces a disaster (Bankoff, Frerks and Hilhorst 2004: 11).

'Vulnerability' thus results from interactions with external risk factors. It describes the "fragile and contingent nature of personhood. Thus we are all 'vulnerable' in some respect" (Beckett 2006: 3). Beckett (2006) suggests that welfare states should take on a widespread understanding of the 'vulnerability' of personhood, in order to respond to the needs of its citizens in an appropriate manner. Yet she also asserts that presently the political will to foster such a model of citizenship does not exist in the UK. Instead, some social groups are singled out and labeled as particularly 'vulnerable', such as women, children, older adults and disabled people. Their condition of 'vulnerability' is contrasted with the assumed resistance of the able-bodied, working-aged male. Instead of acknowledging 'vulnerability' as an integral part of the human condition, we assume that the 'vulnerability' of those labeled as such is fundamentally different (M Brown 1998). We consequently enforce special measures to protect these individuals.

This chapter focuses on exploring 'vulnerability' to sexual violence of disabled adults. It introduces an ecological model that provides a tool for explaining the construction and creation of sexual 'vulnerability'. It is explained how and why disempowerment and control in the lives of disabled people reinforce sexual 'vulnerability'. The discussion draws on a sample of case studies of adults with learning difficulties, yet it must be noted that the ecological model can be utilised to describe the situation of all disabled people.

Methodology

This chapter is based on a Leeds University funded PhD research project, which explored the social forces that impact on the ability of adults with learning difficulties to resist sexual violence.

My initial interest in this topic was raised during a work placement as a social work student in a sexual health agency, where I was involved in instigating an adult protection procedure for a young woman with learning difficulties, Genie. (All names that are mentioned in this chapter are pseudonyms). Genie had confided in me that a member of her extended family had sexually violated her. She approached me for advice on how to prevent future incidents. She was adamant from the start that she did not want to report her violator and that she wished the matter was dealt with discreetly. She feared it would upset her family if it came to light. Yet, as she was considered to be a 'vulnerable' adult and in need of special protection her wishes were overruled. My agency launched a full 'adult abuse investigation', in line with the existing policy guidance at the time (Department of Health 2000), which encouraged multi-agency working. Social services and the police became involved. Staff members at Genie's residential service and at her College were informed. During the police

interview Genie eventually denied she had ever made an allegation. This was not the support she had sought.

Later, while I practiced as a social worker for adults with learning difficulties, policy guidance was revised (Association of Directors of Social Services 2005), yet I remained unconvinced that adults were sufficiently involved in their own 'adult protection procedure'. In fact, some individuals were unaware that investigations were even going on.

Are we right to assume that disabled adults are unable to manage the risk of sexual violence and unable to make decisions about how their protection should be facilitated? Are they inherently 'vulnerable'? Or is their increased risk socially created? In order to answer these questions, this research explored the following specific questions in interviews with people with learning difficulties: To what extent do individuals possess the skills needed to self-defend? What helps or hinders self-defense and the attainment of self-defense skills?

I began the research with a detailed review of the literature, with the aim to gain an overview of the forces that are considered to impact on the risk of sexual violence against disabled adults. These are summarised in the ecological model, which is presented later on (see Figure 1). I aimed to explore how these forces impact on the lives of individuals. With the help of a group of self-advocates, who agreed to act as consultants on the project (Chappell 2000), a semi-structured interviewing schedule was designed. Considerable effort was made to phrase questions in plain language. Questions were accompanied by pictures to enhance understanding. Furthermore three risk perception vignettes were developed. They consisted of eight photographs each that illustrated a simple story line.

I interviewed twelve men and seventeen women with learning difficulties, aged 22 to 68. About half of the respondents had additional impairment labels, including epilepsy, physical and sensory impairments and autistic spectrum labels. Respondents were approached at two-day services and two advocacy agencies, where I also conducted participant observations. Interviews were completed in two or more parts to accommodate for the respondent's concentration span. This chapter summarises some of the preliminary findings of this study.

The nature of violence

We commonly use the term 'sexual abuse' to describe incidents of sexual violation against disabled adults, older adults and young people (eg Association of Directors of Social Services 2005, Whitaker, Le, Hanson, Baker, McMahon, Ryan, Klein and Rice 2008) but 'harassment', 'assault' and 'rape' to describe the experiences of non-disabled adults (eg Kelly 1988). This differing terminology distorts the fact that sexual violence is a similar experience for disabled and non-disabled adults and for working-aged adults, young people and older adults. In this chapter, the more commonly used term 'sexual abuse' is consequently replaced by the term 'sexual violence'. (Please note that the accessible summary uses the term 'sexual abuse'. The research reference group advised me that this term is easier to understand for people with learning difficulties).

It is commonly acknowledged that disabled people are exposed to a

high risk of sexual violence. Shakespeare et al. (1996) report that almost 50 per cent of their sample of disabled men and women had experienced incidents of sexual violence at some point in their lives. Depending on the research study and sample criteria, figures on the prevalence of sexual violence against people with learning difficulties vary from around 10 to 80 per cent (Cambridge 2007). It is often assumed that there is a causal link between impairment and the likelihood of experiencing sexual violence (Association of Directors of Social Services 2005, Department of Health 2000, Mencap 2001).

Yet, the conceptualization of risk of sexual violence through individual 'vulnerability', a label that is often applied to disabled people, focuses analysis on the person at risk rather than on external risk factors. Considering risk in this way is too simplistic. As outlined earlier, 'vulnerability' must be understood as a relationship between individuals and their environments. Perpetrators target disabled people because there appears to be more social opportunity to violate (Shakespeare, Gillespie-Sells and Davies 1996). How and why this happens is explored in the subsequent section.

In the 1980s the realisation of young women's disempowerment in the event of an unwanted sexual approach gave rise to 'Just Say No!' training for those who were considered at risk (Kidder, Boell and Moyer 1983). Yet, as Kitzinger and Frith (1999) have shown, refusal in everyday conversation is rarely limited to a simple 'no'. It often involves various elements of interaction, including delay or apologies. Their analysis demonstrates that women are able to say 'no' in this more subtle manner, but the problem is that they are not being heard (Kitzinger and Frith 1999). This suggests that causes for violence lie with the violators who choose to ignore a person's refusal and not with the injured party.

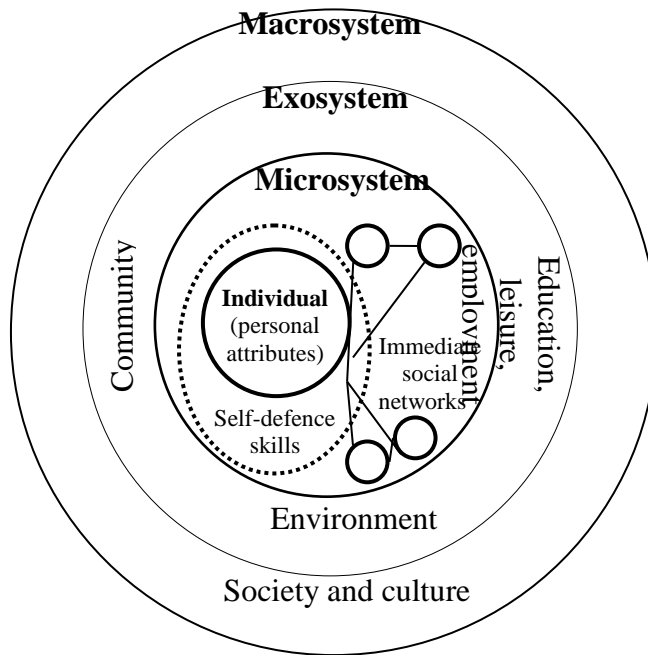
Furthermore, Hingsburger (1995) argues that it is not sufficient to send disempowered individuals on sex education training where they learn that they have the right to make choices about what happens to their body and to say 'no', if they do not have these options in their everyday life. As soon as these participants return to a home environment in which they are disabled from making choices, from being private and being in control of their bodies, they will forget what they have learned or realise that self-determination is not possible in their lives.

It emerges therefore that sexual violence is thus a complex social phenomenon. It occurs in a society that accepts that some people have power and some are disempowered by both structure and agency. As long as such power imbalances are allowed to exist, those who are in a less powerful situation will continue to be at an increased risk of violence.

The origin of risk within an ecological model

This chapter bases the discussion of risk within an ecological model (see Figure 1). The ecological model has previously been presented in *The British Journal of Social Work* (Hollomotz 2009). It brings together the literature about sexual violence against disabled people and builds on existing models (Sobsey 1994, N Thompson 2006).

Figure 1: The origin of risk of sexual violence



The significance of this approach is that the concept 'vulnerability' can be examined within a social model frame of reference. It is acknowledged that individuals are disabled by a society that fails to accommodate for their needs and which forces them to lead marginal, disempowered lives (eg Oliver 1996). An increased risk of sexual violence is not seen as personal inadequacy, but as socially created.

The ecological model incorporates five groups of risk factors to sexual violence within three systems:

- *Microsystem:* individual (personal attributes, self-defense skills) and his or her 'home' environment;
- *Exosystem:* neighbourhood and communities;
- *Macrosystem:* wider culture and society.

The individual's *personal attributes* are at the centre of the ecological model. They include age, generation, gender, impairments, ethnicity, sexuality, culture, religion, economic status, social class and so on. These personal attributes determine the social position of individuals within a society that is characterised by power relations. Impairments (eg Association of Directors of Social Services 2005), age and gender are significant risk factors (Myhill and Allen 2002), with young women and disabled people at an increased risk of sexual violence.

Self-defense skills are a flexible part of the individual. They are shaped and developed through interactions with the environment (micro-, exo- and macrosystem). To explore how this happens is the objective of this chapter. The literature suggests that self-defense skills include:

- knowledge about sex and sexuality (eg Fairbairn, Rowley and Bowen 1995, Foundation for People with Learning Disabilities 2001, Hingsburger 1995), which includes the ability to distinguish sexual behaviours from personal 'care' (eg Foundation for People with Learning Disabilities 2001, Milligan and Neufeldt 2001), the vocabulary needed to report sexual violence (eg Westcott 1993), social awareness to detect or anticipate sexually violating situations (eg Fairbairn *et al.* 1995, Mencap 2001) and the awareness of one's right to resist sexual contact (eg Hingsburger 1995);
- feeling in control over what is happening to one's body (Hingsburger 1995, Westcott and Cross 1996) and privacy awareness (Shakespeare *et al.* 1996);
- self-esteem needed to effectively resist an unwanted sexual approach (eg Hingsburger 1995, Westcott 1993);
- ability to make decisions (Hingsburger 1995).

A focus on individual attributes and self-defense skills in explaining the origin of risk could reflect an individual model approach to disability, unless care is taken to include the social factors. The individual, protected by self-defense skills, is situated within a *microsystem*—the 'home' environment. This consists of an individual's immediate social network, typically family members or support workers and fellow residents.

How others interact with an individual within their 'home' environment is crucial to the formation of self-defenses. Hendey and Pascall (1998: 424) report that some young disabled adults "felt that parents' concern for safety made a child-like and regulated existence beyond the years of childhood." Overprotection is a hindrance to disabled people's self-determination, while it does not prevent sexual violence: Most cases of sexual violence are perpetrated by a known and trusted person. It is estimated that only 8 per cent of rapes are committed by strangers (Myhill and Allen 2002).

The risk of violence and exploitation increases within 'caring relationships' because of the intimacy they invite and particularly if they contain an element of dependency (Hendey and Pascall 1998). Institutionalisation increases the risk of sexual violence, due to depersonalisation, lack of autonomy and choices and lack of communication with the outside world (Shakespeare *et al.* 1996). Isolation and over-protection within a microsystem are consequently not effective mechanisms to prevent sexual violence.

The microsystem is embedded within an *exosystem*—the immediate environment within which the 'home' is situated. This consists of the neighbourhood and social divisions. All community-based activities, such as education, leisure, employment and day-'care', are part of the exosystem.

In order to break a cycle of violence, most individuals require the support of others (Calderbank 2000). In the past allegation of violence against disabled people have been met with disbelief (eg Calderbank 2000, Mencap 2001, Westcott and Cross 1996). In order to access help, the availability of someone who listens, either for signs of violence or when violence is being reported, is therefore crucial (Hingsburger 1995). The more people who are prepared to listen are present in the individual's micro- and exosystem, the higher is the likelihood that violence can be detected and

stopped.

Finally, the exosystem is embedded in the *macrosystem*—the wider society and culture. According to Thompson (2006: 27, original italics), culture refers to:

shared ways of seeing, thinking and doing. It relates to [...] an assumed *consensus* about what is right and what is normal.

There is a general assumption in our society that disabled people are less worthy (eg C Barnes 1990, Ryan and Thomas 1987b), which makes violence against this population appear to be less harmful. Westcott and Cross (1996: 17, original italics) assert that commonly held assumptions take two extremes: People either assume that “nobody would do *that!*”, which means that warning signs are ignored. Or they assume that it does not matter if disabled individuals are violated, as they are “damaged/ unfeeling/ stupid anyway”. This way of thinking would undoubtedly impact on the efforts that are made to detect violence and to protect disabled people.

Social forces and socio-political dimensions, such as laws and social policies, are also located on the macrosystem. In the UK, the *Sexual Offences Act 2003* (HMSO 2003) offers particular protection to adults who are deemed to have no ‘capacity’ to consent to sexual activity and to those who are unable to communicate consent. It outlaws sexual activity between a disabled person and his or her personal assistant, which means that assistants who exploit their position can be prosecuted. Compulsory Criminal Records Bureau checks of staff working with disabled adults were introduced by the *Care Standards Act 2000* (HMSO 2000, part 7). The law can consequently offer and guide protection from sexual violence by acknowledging that some factors, such as personal assistance, increase disabled people’s risk.

The formation of self-defense skills through social interaction

This section examines some of the factors that impact on an individual’s ability to self-defend. Those are: being able to lead positive sexual relationships, an individual’s understanding of sex and sexuality, his or her ability to make decisions in everyday life and his or her sense of self. This structural examination enables us to appreciate shortcomings in these areas as socially created occurrences and not as individual pathology.

Leading Consensual Relationships

This section examines how respondents are enabled and disabled from engaging in relationships. Individuals who are able to lead sexual relationships have an opportunity to increase their self-defenses, as this gives them the opportunity to practice sexual autonomy and to become aware of their sexual likes and dislikes. However, many respondents had limited opportunities for such positive sexual exploration.

Rose, a woman in her mid-40s, has known her partner since they were children. They met at “special school”, fell in love when they were teenagers and got engaged. Yet, unlike non-disabled couples who have been in a relationship for almost 30 years, the couple only see each other at “work” (the day centre). Josie has met a man she refers to as her “boyfriend”

only once, at a social event several months ago. They do not routinely meet and their only contact is by phone.

Andrea: Could you go out and see him at his house?

Josie: No. ... They won't allow us to go out on our own, our staff. They're too protective to us.

Martha states that she cannot see her boyfriend as regularly as she wants to see him, because there are often not enough staff members available to facilitate contact. Comparable complaints were made by a number of other respondents. This indicates that some disabled people do still not have the opportunity to determine how they would like to lead their sexual relationships. Similar findings have been highlighted by past research (eg C Barnes 1990, McCarthy 1999).

Some respondents, like Peter, told me that the only way they could be private with their partner would be to sneak out to isolated places:

You can go out, out there [...] go outside and you can go outside and spend that [...] have a sexy, a sexy half hour or eh, five minutes with your girlfriend.

McCarthy (1999) observed that sexual activity of people with learning difficulties in institutional settings mostly takes place outdoors or in isolated semi-private places indoors (e.g. in unused rooms). Such rushed sexual activity allows little space for negotiations of personal boundaries. Consequently individuals have limited time to consider whether they consent to a proposed sexual act and to communicate their decision. This places them at risk.

Not all respondents were disabled from determining how they lead their relationships. Rachel had been allowed to move in with her boyfriend. The couple were supported by an agency during daytime hours and allowed privacy at night. After about a year, however, her boyfriend became physically violent towards her. Rachel sought support from the agency, which immediately helped her to move out.

Unfortunately, we can never say for certain whether a relationship will remain positive or whether it may turn into an upsetting experience. Support staff and family members are often eager to protect individuals from negative experiences, but as a self-advocate once pointed out to me:

Some relationships work out, some don't. But the person with learning difficulties should be able to try to make it work (Hollomotz 2008: 4).

Individuals should be allowed to take positive risks whenever possible, with support when necessary, as this will increase their autonomy. This experience was painful for Rachel, but nobody could have predicted this change in her boyfriend's behaviour. Rachel was allowed to experience her relationship, with all its positive and negative components, in the same way as a non-disabled woman would have done.

Lee is happily in love. He has been going out with his fiancé for a couple of years. They used to go to school together, but do currently not

attend the same service. Lee therefore visits her at least once per week. Both families are supportive of their relationship. This support is crucial, as Lee and his girlfriend are unable to meet up without assistance.

A positive relationship, feeling loved and wanted, can have a positive impact on an individual's sense of self and happiness. Kathy has been in a relationship for eight years: "He loves me. Call me cute, gorgeous... sweetheart.. and tooth. And he's [laughs] [*laughs while speaking*] He's lovely! [laughs] His love makes me happy!"

This section examined how individuals experience sexual relationships. Some respondents described disabling barriers that hindered them from leading their relationships in the way they choose to. Those barriers tended to be caused by a lack of support from family members and paid staff. Respondents reported practical difficulties, such as lack of staff to facilitate contact with their partner. Other respondents were supported to experience sexual relationships. Although these were not always positive experiences, these respondents were able to explore and become more aware of their own sexuality and to practice sexual autonomy.

Understanding Sex and Sexuality

Respondent's knowledge of sex and sexuality varied. Almost all had some basic knowledge of the mechanics of sexual intercourse and all were able to name their own sexual body parts. A quarter struggled with naming sexual body parts of the opposite sex. Respondent's level of knowledge of Sexually Transmitted Infections and contraception tended to be much lower. Only five of the younger and more articulate respondents conveyed a good level of understanding. Yet it must be noted that this fairly abstract knowledge is not essential when it comes to distinguishing an unwanted sexual approach from a wanted one. Although it could be recommended that more accessible sex education on these topics should be provided to people with learning difficulties, in order to benefit their sexual health, lack of knowledge in this area cannot be blamed for the high incidence of sexual violence against this population.

Disabled people do not live in a protected vacuum. They are not helpless 'victims' of the inferior sex education they may receive. Many respondents demonstrated that they were able to pick up on messages about sex and sexuality from the media and their immediate environment: Mary knows that, over 30 years ago, her sister "had to get married", because she was pregnant. She also knows that her sister used to "go with other married men". However her family never spoke directly to Mary about these issues. She learned about them by overhearing other people's conversations.

Rose has learned about the mechanics of heterosexual sex through the media: "I've seen it [...] all before on TV and everything. And that's got me going." In other words, the fact that Rose had no formal sex education did not prevent her from finding out about sex. Information about sexuality has become more widely available on television, a medium that is more accessible for people with learning difficulties than written information. For example, *The Sex Education Show*, a six part series that captured a "wide range of different personal experiences of sexual issues and problems, as well as offering candid advice" (Channel 4 2008) was aired in the UK in

autumn 2008.

Homosexuality has rarely been discussed formally with respondents. Yet the knowledge that sexual activity can occur amongst individuals of the same sex is crucial, as it enables us to make informed choices about our sexual preferences and to detect an unsought sexual approach by a member of the same sex. Bill is aware of gay relationships, because he has heard that Elton John married a man (eg BBC News 2005b). Many respondents are aware of gay television characters, such as Craig Dean on *Hollyoaks* (Green 2008) and Debbie and Jasmine on *Emmerdale* (Hadrian 2006). For example, Sue draws directly on her knowledge from watching television in her response to a risk perception vignette, in which a female assistant makes a sexual advance towards a woman she works for:

Really, she shouldn't done that. [...] like they are gay. Like what used to be on the telly. ... Can't ya remember on, eh, Emmerdale Farm? ... Then when she were kissing that other lady.... She could, it could get like that, couldn't it?

Individuals' knowledge of sex and sexuality furthermore increased when they were able to experience sex themselves. For example, Britney describes that her first sexual encounter with her ex-fiancé was in a car, while another couple was having sex as well. Britney found this "really embarrassing" and insisted that she would only have sex in a private setting thereafter. In other words, her 'embarrassing' sexual experience taught her about her own preferences.

Some respondents had received information about sex that was discouraging. Ann, for example, states: "They said to me... with sex, sex's a bit.. rude." Gemma also states that "making love" is a "rude" word. Norman believes that masturbation in private is the only acceptable sexual behaviour. Some respondents have consequently voiced the belief that sex is "bad". This had a damaging impact on their understanding and often resulted in self-blame and prohibition.

Tyler was raped by his roommate at residential school. When this happened he did not know that sexual activity could occur between two men and that touching another person's genitals can be sexual behaviour. He states that it was this lack of knowledge that disabled him from self-defense:

I think with a person with a learning disability, I think like me, if they didn't get the proper education and stuff, they're gonna be very vulnerable. If they've got the proper education: They got told: This is a blow job. This is a, you know, they've got all the sexual phrases, you know. Blow job. Pussy. Clit. [...] If they knew all those things and they know what they said was right and what they said was wrong, you know, they'll be learning and they wouldn't be so vulnerable.

Tyler indicates that in the past his lack of knowledge about sexuality had put him at risk. However he has now been able to learn about sexuality through peer talk at College, personal experiences and conversations with support workers.

Although many respondents have stated that watching television has

enabled their understanding of sex and sexuality, others were confused about what they saw. Individuals should therefore be able to talk openly about sex to a person in their immediate environment. Georgina states that she was always able to speak to her mother or brother. For example, once one of her ex-boyfriends asked her for a “threesome”. Georgina was unsure what he meant and asked her brother about this, who explained it to her. She was then able to make the decision that “this is not for me”. Georgina communicated this to her boyfriend. When he insisted, she ended the relationship.

The data presented in this section suggests that some disabled people are exposed to substandard information about sexuality at segregated locations. This is confirmed by past research (eg Gill 1996, Grieve, McLaren and Lindsay 2007, Shakespeare *et al.* 1996). Tyler indicated that this had put him at risk in the past. Yet he and many other respondents described that they were able to learn about sex and sexuality through alternative means of information: The popular media is a major informant. Peer talk and being able to speak to support workers and family members have also been identified as helpful.

The Ability to Make Decisions

In my research I took a particular interest in examining how respondents make decisions in their everyday lives. Interviews consequently explored how individuals made choices about food, clothes, daytime activities, personal support and relationships. It emerged that individuals had more control in some areas of their life than in others. On average individuals had the highest level of control when making food choices. It appears that individuals had less autonomy the more significant the consequences of the choices that were to be made would be. For example, many individuals had no choice about attending segregated day services. Nevertheless, all had an element of control in determining their activities whilst they were at the service. Choosing from this limited and preselected range of options appears almost tokenistic.

All 29 respondents reported that they had some aspect of control over what they ate. Even individuals who were not involved in shopping for food and food preparation stated that they felt confident in refusing food and that they would be offered alternatives. The only exception was Mary, who reported witnessing incidents of force-feeding at her hostel and being scared into eating certain foods to benefit her health, such as cabbage. Staff stated otherwise “she would get cancer”. On first sight it appears that, in respect to food, most individuals with learning difficulties are generally encouraged to make choices, in line with UK government guidelines that stipulate that individuals should be encouraged to be autonomous (Department of Health 2001, 2009). This indicates a shift away from a domination of institutional practices of force and control, as described by Mary, as well as academic sources (eg Ryan and Thomas 1987a).

However, in some cases external control appears to have slipped in through the back door of dieting for health reasons. Smyth and Bell (2006) argue that people with learning difficulties should not be allowed to make their own decisions about food if they would otherwise make unsafe and unhealthy decisions. They call for an increase of control in the lives of those

disabled individuals who are considered to make unhealthy decisions, although this contradicts the *Mental Capacity Act 2005* (HMSO 2005), which gives individuals the right to make an unwise decision, as long as they can remember that decision and understand the consequences.

Sue, who appears to be of a perfectly healthy weight, follows the *Weight Watchers* (2009) regime. She proudly pointed out the lower fat content in diet biscuits in front of her key worker, who smiled and said: "You see, she knows it all herself. It's her choice." Yet, away from her home at the advocacy training, Sue never failed to buy herself a bag of high fat crisps and to ask for a second serving of the chocolates and (non-diet) biscuits that were available as refreshments. The fact that Sue's eating behaviour is very different away from home makes me wonder whether she genuinely prefers to diet.

When choosing clothes the control exercised by others was more obvious. Many of the women were inhibited in their choices when deciding what clothes to buy. McCarthy (1998) reports similar findings. Clothes choices are important in expressing who we are and how we would like others to see us and also when it comes to expressing a sexual identity (Gleeson and Frith 2004). It was this sexual identity that others appeared to be eager to control:

- Andrea: Have you ever been in a shop, when you wanted to buy something and the staff said: "No, you can't have that!"
- Martha: [2 seconds] You have to c.. cope with it.
- Andrea: You have to cope with it? [...]
- Martha: Like a grown up.. I have to act like a grown up.. when she says "no" to things.
- Andrea: But why would she say "no" to things?
- Martha: Because if it's too-, showing all your... breast off. She won't let me have.. a top.

Such accounts were common amongst women who were accompanied by staff or family members when shopping for clothes. Martha and I spoke to her key worker after the interview to clarify why Martha is not allowed to buy some of the clothes she likes. The key worker explained that surely Martha would not feel comfortable in less modest clothes and that she would advise her own daughter not to wear these styles either. But how would Martha know whether she feels comfortable in a low-cut top, if she is not given a chance to find out for herself? Moreover Martha is an adult in her 30s and not her key worker's child. The fact that Martha believes that sometimes she has to act "like a grown-up" may suggest that she has internalised the infantilisation she is subjected to, which inevitably impacts on her sense of self.

This section has merely touched on the disablement that many individuals encounter when negotiating food and clothes choices in interaction with others within their 'home'. Individual's accounts suggest that the lack of resistance that is said to characterise disabled people may result from disempowerment in their everyday lives: Martha's attempts to exercise self-determination are crushed. Sue presents a willingness to please her assistants. Lack of control over how they present themselves and exclusion

from adult status (Priestley 2003) hinder the formation of confident, independent adult identities. The subsequent section explores further impacts on an individuals' sense of self.

Developing a Sense of Self

As chapter four will outline, disabled people are exposed to predominantly negative images of disability (eg on television, Cumberbatch and Gauntlett 2006). Measured against a non-disabled 'norm', impaired bodies are viewed as 'imperfect' and 'inferior' (eg C Barnes and Mercer 2008, Morris 1991) or exposed to the spectator's fascinated gaze, as in the UK television series *Extraordinary People* (Channel 5 2009). Finkelstein (1987: 4) argues that it is therefore "essential for [disabled people] to create our own public image, based on free acceptance of our distinctive group identity." The self-advocacy and disabled people's movements aim to challenge negative assumptions of inability and incompetence (eg Central England People First 2000). Yet disabled people are often socially excluded and isolated or forced into segregated settings (Oliver 1996). This may prevent some individuals from becoming aware of disability activism, such as their local self-advocacy group. Exclusion and isolation within segregated environments furthermore limit the lifestyle consumption of disabled people and with this their scope for actively accomplishing a positive identity (C Barnes and Mercer 2008).

Not surprisingly many respondents had developed a negative sense of self. Chantal, for example, states: "I wish I were normal like everybody else and I wish .. I didn't have a learning difficulty." Richard blames his impairment for the segregation he experienced when he was sent to a "special school". Paul blames his wheelchair and not the built environment for being unable to overcome physical disabling barriers. In other words, many respondents conceptualised disability as their individual 'problem' and not as a social one.

As a consequence of the stigma that is attached to it (Hunt 1966), many individuals distanced themselves from the category of 'disabled people' (Prime Minister's Strategy Unit 2005). One respondent explained that, if others found out about her impairment "they'd probably treat you bad. They'd say you're a freak, or whatever cause you're different." Ryan asserts that he always felt that he had to compensate for his "individual shortcomings":

I've always tried pleasing people in my life, cause that's with my difficulty, that's what I've always thought I've had to do. [...] I've always tried to prove that I can do things, when really I can't.

Yet this willingness to please makes individuals particularly 'vulnerable' to experience sexual violence. Negative images of disability and the oppressive treatment they experience have a detrimental impact upon the sense of self of individuals. This results in low self-esteem, denial and apolitical individual battles against impairment effects.

Bob was one of the few respondents who had a positive disability identity:

My parents have said that it's kind of, the Autism that kind of, like,

makes some people, like, better at things... And I think that's why I'm good at computers.

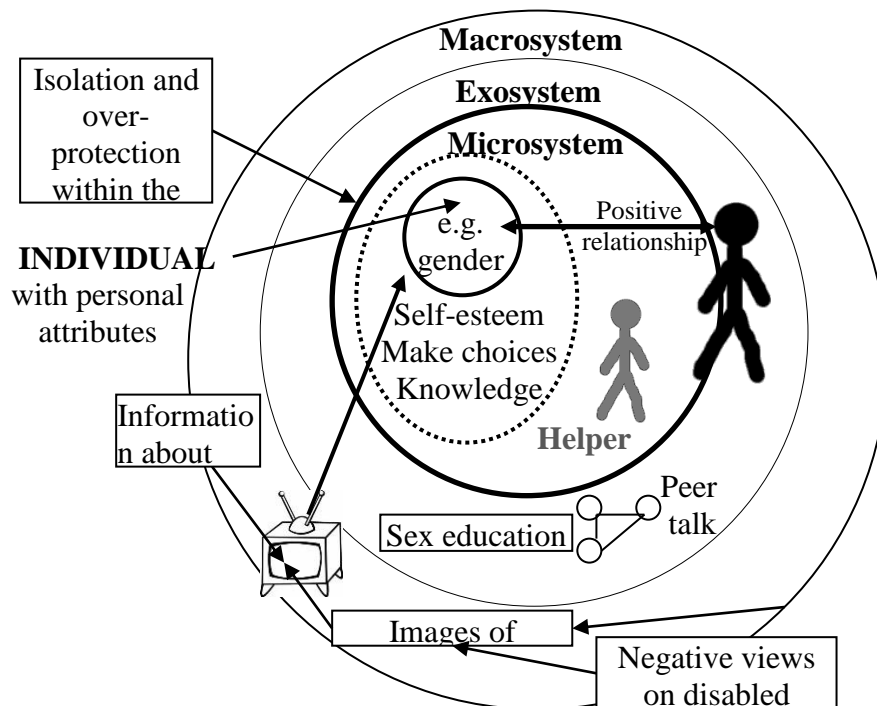
Bob explained that he has not always been this confident, but that he has learned to believe in himself as he grew older. At the time of the interview Bob was studying to be an IT technician in a mainstream environment. Bob has liberated himself from the negativity that is often implied in impairment labelling. He is proud to be on the Autistic spectrum and he does not wish to change. He describes a supportive family, friends and educational environment. This has enabled him to believe in himself and encouraged him to aim high. He refers to positive role models, such as Isaac Newton, about whose suspected Autistic spectrum label he has heard on the news (eg BBC News 2003).

Bob's case demonstrates that individuals do not necessarily have to perceive their impairment as a disadvantage or as an individual 'problem'. The fact that many respondents in this study felt this way reflects assumptions about the undesirability of physical and cognitive diversity that prevail in our society. As Ryan describes, this may result in low self-esteem, individual battles against impairment effects and a willingness to please. All of these factors increase the risk that a sexual attack may succeed.

Conclusion

This chapter examined some of the social factors that have the potential to increase or reduce 'vulnerability'. Some of the patterns that emerged from the data are summarised in Figure 2.

Figure 2: Social risk factors and enabling forces



Personal attributes of the individual determine how others respond to that person. For example, in comparison to men, women with learning difficulties experience an increased level of disempowerment when making choices about clothes. Helpers advocate modest styles to suppress the woman's overt expression of sexuality.

The helper is a key figure in the individual's life. A helper may be a family member, spouse or support worker. Many disabled people have more than one helper. Georgina, for example, mentioned her brother and mother, while Martha referred to a group of support staff. As with most women's clothes choices, helpers may hinder a person from making independent decisions. Conversely the helper could enable an individual to make more informed decisions: When Georgina was unsure what a 'threesome' was, she asked her brother to explain this to her. She was then able to decide for herself whether she wanted to go along with her boyfriend's proposal or not.

The helper can enable individuals to access information about sexuality, either by answering questions themselves or by assisting the individual to access information services, such as their local family planning clinic. Even in the absence of such help television has enabled many individuals to learn about different aspects of sexuality. This factor is based on the macrosystem, yet it is consumed in the microsystem and has the advantage that it is easier to access than e.g. written information and services on the exosystem.

The helper can act as a link person to facilitate a relationship. Lee, for example, describes how contact with his girlfriend is arranged by their parents. Others, like Rose, report that the helpers in their microsystem do not support their relationships. This results in individual's disablement from leading the relationships they want. Yet being able to lead positive, consenting relationships can increase sexual self-awareness and self-esteem, important factors that reduce the risk that a sexual attack may succeed.

Some individuals described containment, isolation and over-protection within the microsystem. For example, it was briefly mentioned that some respondents had no choice about whether or not to attend day centres. Individuals who were able to access facilities in the community experienced this as positive. Tyler, for example, states that he has gained knowledge about sex through peer talk at College.

Negative views on disability that prevail in society, as well as the lower lifestyle consumption and marginal positions that disabled people are often forced to adopt, may lower individual's self-esteem. However Bob's example demonstrates that positive disabled role models and encouraging helpers can enable increased self-esteem.

It must be remembered that risk or 'vulnerability' is negotiated between individuals and their environments. It is not sufficient to train disempowered individuals to 'Just say no!' or to focus on an individual's lack of self-defense skills as the cause of violence. The suggestion that sexual violence can only be stopped by protecting those who are at an increased level of risk is individualising and often ineffective. Instead we must focus our

gaze beyond individual 'vulnerability'. Increased risk to sexual violence is, at least in part, socially created and re-enforced. Sexual violence occurs in societies that allow some individuals to have power over others. As long as disabled people have a marginalised status, the risk will remain high. Preventative work should therefore focus on removing disabling barriers, ending oppression and allowing disabled people to exercise autonomy in their sexual and everyday lives.

CHAPTER 3

Members Only: The Use of Gay Space(s) by Gay Disabled Men

Craig Blyth

Accessible Summary

This chapter talks about the experiences of disabled men who are gay. The chapter is based on research that the author did with some disabled gay men who wanted to spend some time in a part of Manchester (in the UK) that lots of gay men go to called the Village. The research found that disabled gay men can find it very difficult to spend time in the bars and clubs in the Village. The main things that the research found were:

- There are lots of bars and clubs that people who use wheelchairs cannot get into.
- The bars and clubs in the Village advertise themselves using lots of pictures of young men with big muscles who are not disabled.
- Lots of the men that spend time in the Village think that all gay men should look like the men in these pictures.
- Because there are lots of pictures of these types of men all around the Village it can make some disabled people feel that they do not fit in.
- Some non-disabled gay men think that disabled men cannot be gay.
- Some of the disabled men who helped with the research felt angry at the way they are treated in the Village and are trying to change things.
- When some of the men in the research go to the Village they pretend they are not disabled so that they fit in.
- Some disabled men decided that the Village was not a good place for them to go so they use other places to meet other gay men.
- The other places that some of the men go to meet other gay men include public toilets and the Internet.

All of the men in the project felt that they were shut out of the Village. This made some of the men feel bad about themselves. Being made to feel this way about yourself and your sexuality can be very disabling and the author thinks that people that teach disability studies should do more research about this.

Introduction: The Unwitting Ethnographer

“The history of any inquiry begins with something that is less than a problem... It may be considered as an awareness that there is a question to be asked” (Ravetz 1971: 135).

My awareness that there was ‘*a question to be asked*’, in relation to Manchester’s Gay Village and disabled people, began over ten-years ago. As a young gay man who had moved from a small city to the much larger and more sexually ‘cosmopolitan’ city of Manchester (UK), I spent much of my early twenties in the restaurants, bars and clubs that make up Manchester’s internationally known Gay Village (largely as a result of the hit UK TV show *Queer as Folk*). It was during this time that I started to recognise (in all honesty, most likely through a ‘gaze of desire’) that there were certain

attributes that many of the men who frequented the Village appeared to share. These attributes centred on, predominately, age and certain bodily attributes. In short, the vast majority of popular venues were overflowing with physically attractive, athletic and mobile young men who appeared to be acting in very similar ways.

During the many hours I spent socialising in the Village, I began to observe and recognise that many of the men around me were presenting a triad of opposing performances. These men appeared to be simultaneously attempting to conform to the hegemonic heterosexual masculine ideal by overtly displaying their 'hypermasculine' physiques, whilst at the same time challenging the heterosexual nature of that version of masculinity through the use of their 'masculine' bodies to sexually attract other men. The final element of these performances centred on creating an alternative bodily hegemony within the 'gay space' these men occupied that positions men with certain physical attributes as dominant over those who did not possess similar bodily qualities.

As an academic teaching and researching in the field of disability studies, these observations formed the basis of my interest in how these versions of masculinities serve, not only as the basis for a range of scripts that many non-disabled gay men 'perform' when spending time in the Village, but also how these versions of masculinity can impact on disabled gay men's ability to become part of a group of men that spend much of their time in commercial gay spaces.

In this chapter, I explore the complexities of negotiating access to gay space by men who do not conform to what has become the hegemonic normative gay version of masculinity.

The Village

Manchester is a large city that is located within the North West of England. Following somewhat of a renaissance in the 1980's, Manchester has developed a reputation as being a young, vibrant and dynamic city. The city is now host to numerous bars, nightclubs, restaurants, theatres, museums and a variety of other social spaces.

The Gay Village can be found at the heart of the city and has been described as "the strongest and most vibrant Lesbian and Gay Community in the country" (Healthy Gay Manchester 1998). Although, there has been a gay 'presence' in the geographical area since the early 1900's the Gay 'Village', as it is recognised today, really began to develop during the 1980's.

It has been suggested that the impetus for the development of such an open and visual gay space was a response to the extremely homophobic treatment of gay men during the late 1980's (Binnie and Skeggs 2004). Whilst, a Conservative government was introducing homophobic legislation to prevent equality for gay people across England and Wales, the situation in Manchester was particularly oppressive as a result of an aggressive homophobic policing policy. The attitude of the police at the time towards gay men who accessed the Village can be illustrated by the words of James Anderton, the then Chief Constable of Greater Manchester Police, who declared "Homosexuals are swirling around in a cesspool of their own making" (Greenberg 1988: 478).

The response by large numbers of gay men to these oppressive policies and attitudes was the consolidation of the gay 'community' and the development of a far larger and increasingly visible gay space. Today, the Village is made up of over 60 commercial 'gay' businesses including bars, clubs, restaurants, saunas and retail outlets. The outskirts of the Village are rapidly being expanded by the development of large 'city living' apartment complexes that are specifically marketed at gay people.

The Village provides a whole range of social spaces for gay men to meet and socialise. It has been also noted that gay spaces such as the Village play a significant role in the "forging of gay men's social and sexual lifestyles" (Valentine and Skelton 2003: 849). For many young gay men, or men considering 'coming out' as gay, the ability to spend time in the Village can play a significant role in the formation of a gay identity (*ibid*). It is widely recognised that the process of 'coming-out' can be both lengthy, emotionally challenging and for some painfully difficult. However, Dowsett (1993), when discussing the process of identifying as gay, suggests that commercial gay spaces such as the Village offer gay men the opportunity to not only develop 'narrow' gay identities (i.e. men who have sex with men) but to also move beyond an identity purely focused on sexual orientation to

a fully fleshed sexual subjectivity... in which "gay" encodes more than sex; it encompasses an internalized identity as gay, a citizenship,... (Dowsett 1993: 703).

Dowsett goes on to suggest that becoming part of a gay 'community' can offer a "solution to that painful difficulty" that many actively gay men who are unattached to the wider gay 'community' experience. Whilst Dowsett's somewhat utopian vision of what the gay commercial scene can offer gay men is questionable (I would specifically question whether accessing a commercial gay scene could truly be described as being a member of a gay 'community'), I would agree that, for many gay men, the ability to access and feel part of a larger commercial gay scene is a significant part of 'who they are'. In addition to recognising the significance of gay spaces and 'communities' in the lives of many gay men, Dowsett (1993: 703) asserts that "the "gay" option is now *definitely* [my emphasis] available to most homosexual men".

Whilst agreeing with Dowsett that access to commercial gay spaces can offer gay men a range of transformative *possibilities* that relate to areas such as wider social networks, the development of intimate relationships, feelings of belonging and ultimately the development of a positive gay identity, this chapter will explore whether, as Dowsett asserts, this "option is now definitely available to most men" (*ibid*).

Gay Disabled Men and the Limitations of Traditional Disciplines

Whilst sociologists have been theorising and writing about masculinity since the 1950's, masculinity studies, as we know it today, began a fairly rapid expansion during the last twenty years (Connell, Hearn and Kimmel 2005). Until recently, the central theme of this theorising has been concerned with how issues of power are central to man's ability to 'be a man' and how this power is enacted (Whitehead and Barrett 2001). More recently, an alternative

approach has begun to emerge which takes an increasingly postmodernist view of the concept of masculinity, and places an emphasis on how dominant discourses and discursive practices are central to the construction of a range of identities including versions of masculinity (Connell *et al.* 2005, Traister 2000).

However, even with this postmodernist influence, much of the writing relating to masculinity studies has been and continues to be undertaken from the perspective of white, non-disabled, heterosexual, middle-class academics; resulting in a body of work that reflects the values and experiences of this group of people. The result is the emergence of a discipline that is largely concerned with the dominant position of heterosexual men within a hegemonic gender hierarchical society. Traister (2000: 274) highlights the discipline's Heterocentric nature by stating "masculinity studies' has become a code word for 'heterosexual masculinity studies'". The result of the centralisation of heterosexual masculinity within masculinity studies is the production of accounts of masculinity that explicitly and implicitly contribute to the construction and maintenance of heteronormative versions of masculinity. Furthermore, the relative paucity of masculinity writings that explores alternative versions of masculinity and how these relate to the experiences of men with multiple identities (such as being gay, black, disabled etc...) produce an emerging academic discipline that many men would consider does not reflect the lives that they lead.

Masculinity studies are not alone in the omission of any concerted serious consideration of the lives of individuals and groups with multiple identities. Recent decades has seen the discipline of disability studies begin to gain currency amongst academics and academia in general. The publication of texts such as *The Politics of Disablement* (Oliver 1990) provided both the impetus and academic credibility to the emerging discipline (Shakespeare 1998). Readers of Oliver's text will be aware that at the heart of this new discipline was the social model of disability. This model fervently rejects that disability results from bodily impairments and (re)defines disability as what Oliver and Barnes (1998: 3) describe as "a situation of collective institutional discrimination and social oppression". The central tenet of both disability studies and the social model is that disability is a form of social oppression and as such the most appropriate way to address disability is to address the ways in which the organisation of society fails disabled people.

Whilst, a shift in position from viewing disability as a result of individual impairments or 'failings' to one that sees disability firmly resulting from "institutional discrimination and social oppression" (*ibid*) is a position I loudly and explicitly align myself with, I question whether the social model adequately addresses the personal experiences of *all* disabled individuals. Several writers, particularly feminist writers, have highlighted that the social model's focus on the 'public' or societal experience of disability over the 'personal' experience of impairment and disability has resulted in individuals and groups with multiple identities feeling that the social model does not adequately accommodate their lived experiences. Perhaps the most well-known and influential disabled feminist writer in the UK is Jenny Morris who has been at the forefront of questioning the limitations of the social model. Whilst Morris (1996: 12-13) recognises the importance of the social model to the point of stating "It is difficult to overestimate the impact the social model

has had on disabled people's lives" she goes on to add that she finds herself saying "hang on a minute, this isn't quite right".

Morris and other feminist writers contend that the social model is born out of the Marxist perspectives of leading social modellers such as Mike Oliver and Vic Finkelstein and it is they (men) who have prioritised which barriers are of the most significance. Morris and others contend that it is those barriers that are of most relevance to men that have been prioritised. For example, Morris suggests that issues such as assistance with childcare have been overlooked in favour of the barriers related to accessing employment. Whilst agreeing with Morris, I want to go further and suggest that as a result of many of the most ardent social modellers unquestioningly embracing Eurocentric, heteronormative, patriarchal, identity categories and concepts, a social model has been developed that effectively has resulted in 'difference' amongst disabled people (such as race, class, sexuality, gender etc...) being written out of much of the disability studies literature. In essence, much of the work produced to-date simply reflects the hegemony of the white hetero-patriarchal society that we live in (R Butler 1999).

I have so far argued that much of the work being produced from within both disability studies and masculinity studies results in the homogenisation of disabled people into a group that simply reflects the dominant white, patriarchal, heterocentric society we live in. Therefore, I now want to suggest that if academics are to ensure that their work adequately accommodates the lives of *all* disabled people then we must ensure that we (re)examine our own conceptual frameworks. We need to ensure that our own discursive practices do not create work that simply embodies the dominant assumptions that the wider dominant society may hold in relation to individuals that are traditionally viewed as 'other'. After all, as Vernon (1998: 390) states "if you are not part of the solution, you are part of the problem".

Methodological Approaches

Working from a broadly constructionist interpretative paradigm, I carried out a series of interviews with 12 men who identified as both disabled and gay. From the outset of the project, I was aware that if I was not to replicate some of the limiting consequences of the approaches I have previously outlined, it was clear that an approach to the recruitment of participants was needed that ensured that a diversity of individuals and their experiences were included within the project. One of the initial challenges of this project was how to recruit participants. The complexities of recruiting 'hard to reach' groups, including gay men, are well recorded (Heaphy, Weeks and Donovan 1998, Lee 1993, Tross 2001). However, the challenges faced when attempting to recruit men who identify as both gay and disabled and furthermore who accessed a specific 'gay' locality proved to be both complex and, at times, problematic.

It was clear from the outset that if the project was to successfully recruit a range of participants, who either spent time in the Village or who had attempted to access the space, no single approach to the recruitment of participants would be suitable. Single specific approaches such as 'relational outcropping' (Lee 1993), 'snowballing' or targeting certain niche publications (such as gay interest magazines or disabled peoples' organisation's websites) were all considered to have strengths, for example, 'snowballing' would have

been a relatively straight-forward and time efficient method of recruitment. However, it was quickly recognised that as single approaches there were significant limitations related to each. For example, used in isolation of other methods it was likely that each of these approaches would result in the recruitment of men from similar social and cultural positions. Similarly, whilst advertising within the Gay Village would clearly reach large numbers of gay men, it would not reach gay men who felt excluded from the space.

With this in mind, a multi-method approach to recruitment was adopted whereby a combination of the approaches discussed were employed in order that disabled gay men from a range of backgrounds and social and cultural positions could be targeted. The combination of advertising the project widely, snowballing and utilising personal contacts led to a significant number of men who defined themselves as disabled and gay agreeing to participate in the project. At this point, theoretical sampling was adopted whereby the men that finally took part in the project were selected in order to include men from a variety of different backgrounds, socioeconomic groups and who experienced a range of different impairments. Ultimately, it was hoped that by recruiting a group of men with a diverse range of experiences that “identities considered important by respondents themselves” (Heaphy *et al.* 1998: 455) could be explored.

Throughout both the data gathering/construction phase and during the on-going analysis of the data, the interview process was not considered as a tool to produce definitive accounts of ‘what it is really like’ to be disabled and gay but as a method for gathering a range of narratives that would provide some insight into how the participants interpreted and made sense of their experiences (Rodriguez and Ouellette 2000). When analysing transcripts, a framework was developed that enabled me to recognise that the ‘stories’ the transcripts contained were textual representations of “mutually constructed stories” (Sparkes 1998: 74). The recognition that the data in front of me was, in many ways, reflecting aspects of not only the experiences and thoughts of the participants but included reflections of my own experiences enabled me to place myself in the same frame as the participants. By adopting this approach, it was possible to begin to reflexively consider the transcripts in ways that concepts such as ‘difference’ and ‘sameness’ were recognised as significant relational aspects between me and the participants. Rather than being ignored or denied, these relational complexities needed to be recognised as reflecting the situated nature of the narratives produced.

An illustration of how my ‘sameness’ was clearly significant within the interview process is provided by Baz and Clive (a gay couple, both who describe themselves as having learning difficulties) during their first interview with me:

Craig: Where did you both meet?

Baz: erm, I know you’re not suppose to but, we actually, erm
10 second silence

Clive: its ok coz you’re gay’

Baz: In the toilets.

When thinking about Clive and Baz’s words, it is clear that, for them, what they perceived as the ‘sameness’ between the three of us (I openly self-

identified to all potential participants as a gay man) was significant in relation to the stories they told me. The exchange went on to develop into Baz and Clive seeking my opinion of gay men who used public toilets to meet other men for sex. When analysing the data, it became apparent that Baz and Clive would 'test' my views on certain topics before deciding on the next stage of the narrative they provided. For example,

Baz: I know it's illegal but it's been going on for years. It was probably going on before you were born. There's nothing wrong with it really.

Craig: I know that lots of gay men go to toilets to meet other men all the time.

Baz: I have been going in them for years.

Clive: Me too, since I was about 16.

Through close readings of the data, it was possible to see the evolving and shifting nature of the participants (re)interpretation of events and concepts as a direct result of their interactions with me. This and other transcripts analysed highlight how during the interview process "reality is continually under construction" (Holstein and Gubrium 2003: 74) as a direct result of the interactions of the participant and interviewer.

Accessing the Village

There were a number of substantive themes that emerged from the project. Firstly, I briefly explore how physical and attitudinal barriers can impact on disabled gay men's ability to access and spend time within the Village. As the chapter proceeds, the focus of the discussion moves to how the participants in this project respond to and negotiate these barriers.

Physical Access: Structural Exclusion

Without exception, all the participants identified major hurdles to accessing the Village as a lack of physical access to the vast majority of the venues. Whilst, the lack of appropriate physical access is, for many disabled people, an every day disabling reality, many of the participants suggested that the lack of access within the Village was particularly significant in relation to their ability to develop their identity as gay men. Henry, discussed how on many occasions he had left the Village unable to access the vast majority of venues,

I can only go to the few bars that have lifts in them as the majority of them are either upstairs or downstairs. The other day I thought I would go to Cresta [name changed] as it had a lift. When we got there the lift was not working, so then you have to search around for someone. They wouldn't let my friends carry me in because of insurance... I would spend much more time in the Village if I could get in most places.

For Henry, the lack of physical access in the Village served to immediately reinforce feelings of 'difference' from the non-disabled men around him (Morris 1991). Whilst a lack of physical access is a common experience for many disabled people in society, this particular example highlights how many disabled people "struggle to access the familiar social environs that enable sexual expression" (Sanders 2007: 443). Additionally, the significance of the denial of access to spaces that potentially "*enable sexual expression*" is

compounded for many gay disabled men. Several men within this study discussed how for many years they had received support from family members or paid carers who, through their behaviours or discourses, had imposed a set of heteronormative expectations on them. Having ultimately found the courage to reject these expectations and access a space that symbolically represents a challenge to the dominant normalising discourses it could be argued that the impact on these men is significantly more 'disabling' than the lack of access to other non-gay spaces.

Psycho-Emotional Disablism

Henry went on to discuss how he felt that even when he was able to access one or two of the venues in the Village he believed that it would not lead to him developing relationships with other gay men,

It's about being in the chair, thinking, you know, you wouldn't attract anybody... you were thinking "well what's the point". You just sit in the corner, you just sit and watch because you don't really expect anyone to come and speak to you.

When considering Henry's perspective, there is a risk that one could view his words through the lens of the individual tragedy model; simply put, one analysis of Henry's situation could be that his inability to walk has led to low self-esteem. However, I want to reject this analysis and suggest that Reeve (Reeve 2006: 96) offers a far more helpful framework to consider Henry's views:

This particular dimension of disability which operates along emotional pathways is highly influenced by cultural representations and disabling images ... Negative cultural images and the rejection of impaired bodies from mainstream society have an effect on not only how disabled people see themselves, but also how they are perceived by others. Thus psycho-emotional disablism can be found in ways that some disabled people internalise the negative social values about disability, or within their relationships with family, friends, professionals or strangers.

As previously explored, the body or more precisely the 'perfect' body plays a central role within commercial gay spaces. Tate and George (2001: 163) explore this stating that commercial gay spaces have "a normative preoccupation with looks and youthfulness which often excludes those who cannot conform". Shakespeare (1999a: 50) goes a step further than this and describes how a form of "body fascism" operates within commercial gay spaces. The impact of this on Henry and other men within the project was evident to see. Many of the men described how they believed that they would not be considered attractive by other gay men as they failed to meet these bodily standards. It is true to say that it is not only disabled men who experience the consequences of failing to meet the requirements of what has become the dominant 'ideal' gay man namely "slim, boyish and attractive" (Williamson 1999: 2), the impact of this othering is compounded for gay men. For many gay disabled men gay spaces, symbolically and corporeally, represent not only an area where they can express their gay identities but

also as Valentine and Skelton (2003: 854) state “where others can validate these identities”. The denial of this ability serves only to further other disabled gay men and as Vernon (1998: 203) states, position them as an “Other within an Other”.

In relation to the othering that many of the participants experienced, a number of men discussed how they had developed strategies to avoid this process. It is these strategies that I will now explore.

To Pass or not to Pass?

Alan, a 61-year-old retired academic, discussed how he had concealed his gay identity when not in ‘gay’ environments whilst simultaneously attempting to conceal his visual impairment when spending time in the Village,

Now, I have negotiated my life by [7 second pause] two forms of passing, passing in the African American way; that is to say the way some very pale skin toned African Americans can pass for being white and the other way is the Erving Goffman way.

When interviewing Alan, and during the subsequent analysis, I was struck by the carefully considered choice of words that Alan used to describe how he lived his life, specifically the word ‘passing’ and the direct reference to Goffman’s (1968) influential text *Stigma*. Alan was clear that, for nearly forty years, he felt that when he was in all but the most intimate and close company, whether that be in a professional or social setting, he always felt the need to ‘pass’ as a member of the dominant group, lest he be othered. For example, Alan explained that he would conceal both his gay and disabled identity through a combination of avoiding all conversation that might lead to a discussion regarding relationships and by employing strategies such as:

If I was working with you, the things I might do wrong such as bumping into things, I would just say I was nervous about something or I was preoccupied.

Interestingly, it is not just within ‘real’ gay space that the participants discussed their need to conceal their impairment but also in virtual gay spaces. Henry explained that he regularly uses the internet to meet other gay men and potential romantic partners. He discussed how he regularly conceals his impairment from the men he meets online

If I use the profile that has a photo of me not in my chair, and I type in something rude like what I want to do, you get them all coming and talking to you. Whereas, if I did the same being in a chair, you wouldn’t get hardly anyone coming to talk to you.

It would appear that strategy of ‘passing’ as non-disabled by gay disabled men is not limited to the men in this project. The website *BentVoices.Org* provides a forum for gay disabled men from around the globe to communicate with each other. Whether disabled gay men should attempt ‘to pass or not to pass’ is a hot topic with comments such as,

'I'm not tempted to try and "pass" as non-disabled, only to risk heartbreak later' –Phil, New Zealand

'I have friends who play the "passing" game a lot' – Randy, Ontario

'I've tried at least a hundred different ways, I'm sure, to portray myself on dating sites. From completely omitting my "mark" to explicitly flaunting it' - Phil, New Zealand

For some of the participants, the issue regarding 'passing' was a clear one, conceal their impairments and 'risk' that element of their identity being discovered; what Goffman (1968) termed becoming 'discreditable', or openly reveal their impairments and risk immediate rejection; what Goffman (1968) termed as being immediately identified as 'discredited'.

When discussing whether to 'pass' or not Dan recounted a recent experience in a gay bar in the Village that has led him, on occasions, to conceal his visual impairment from non-disabled gay men,

Well, it happened the other day, he didn't see the dog. We were chatting each other up and then he saw the dog and said "Oh I didn't know they allowed dogs in here" so I explained he was a guide dog. Then his attitude just changed... he said "I'll be back in a minute" and he never came back. It happens nine times out of ten in gay bars.

Eric provides us with a similar narrative, in relation to the reactions he experiences from some non-disabled men he meets online:

One guy said to me, "I think we would get on as friends but we could never be partners because I've got a really high sex drive and we wouldn't get on that way" and I just thought "fuck off, I don't even fancy you!"

Eric's experience illustrates how when he displays a photograph of himself using a wheelchair some non-disabled gay men immediately conclude that as a disabled gay man Eric's ability or desire to engage in sexual activity is diminished. For many disabled gay men, their ability to 'perform' a non-disabled identity is considered by them as a strategy to be employed in order to gain entry or 'membership' to physical or virtual gay communities.

Performing for the Boys

At this point I want to suggest that there are clear connections between how many disabled gay men feel that in order to be seen as a 'viable' gay man they need to 'pass' as a non-disabled man and how many non-disabled gay men feel that they need to enact, through a different set of performative behaviours, a form of hegemonic hyper-masculinity if they are to be considered as the 'ideal' gay man.

Both groups of men, in somewhat similar ways, are presenting a performance that suggests "I possess the attributes that a real man should" whether that be strength, independence, sexual prowess or 20:20 vision. As Tepper (1999: 43) points out, these performances are an attempt to portray

that these men possess a “set of defaults ...that define a fanciful standard of masculinity”.

This “fanciful standard of masculinity”, is created and maintained within much of the commercial gay scene through the creation and maintenance of dominant discourses. These discourses promote a version of heterosexual masculinity as that all ‘true’ gay men should aspire to. A brief walk around the Village, or indeed most commercial gay scenes around the world, reveals images of young, tanned and toned men promoting a whole range of venues and products. The implicit, and often explicit, message is that if you go to this club you will have a chance to meet or even ‘get laid’ by the young attractive men advertising the venue; in essence, privileging the non-disabled ‘perfect’ (athletic) body over all others. The dominance of these images and wider discourses imply that in order to be desirable to other gay men, or indeed to fulfil the requirements of simply being a gay man, individuals need to possess these ‘perfect’ bodily attributes or in the case of many men to conceal parts of their bodies and identities that do not ‘measure up’ to what a gay men should be.

I have so far described how, for some disabled gay men, daily life involves the juggling of a complicated set of performances which are enacted in response to the dominant discourses that construct and maintain particular forms of masculinity in particular environments at particular times. I have described how, for some, the experience of rejection and the constant exposure to disablist assumptions made by many non-disabled gay men can affect aspects of their emotional well-being and therefore lead to a form of psycho-emotional disability (Reeve 2006). Some disabled gay men choose to confront and resist the oppression that exists within the Village by merely being a visible disabled gay man within, what is for many, an oppressive disablist environment or as Eric puts it “they can all fuck off, I’m here, I’m queer, I ain’t going anywhere!”. However, other disabled gay men have decided that the Gay Village is not a space that is open to them.

On the Outskirts

For many of the men participating in the project, their experiences within the Village have resulted in them feeling that it is not a space that they can access. Fred illustrated this when he described how he had given up on the idea of ever meeting a partner (either sexual or romantic). Through the use of metaphor he expressed his belief that this particular space was somewhere where he was unlikely to ever meet a potential romantic partner:

It’s like an exclusive club with them and us... We’re trying to fit in but it’s like I’m not a member of that club and I never will be.

Similar reflections to those revealed by Fred relating to ‘not fitting in’ to the Village are found within the transcripts of many of the interviews undertaken throughout the project. However, it was striking when talking to the majority of the men that they were either in long-term romantic relationships or engaged in regular casual sex with other gay men.

Considering the vast majority of the men’s accounts of their experiences in the Village involved various stories of exclusion and rejection, I was interested to understand how the participants developed these relationships.

In relation to psycho-emotional Disablism, and the overwhelming negative reactions these men received from within the Gay Village, one understandable response could have been for many of these men to 'close' themselves off from the possibility of ever developing intimate or emotional relationships with other gay men. As Shuttleworth (2002: 117) suggests "The possibility of establishing intimacy with others only exists if one remains open towards them".

While it is apparent that a number of the participants, such as Fred, do not remain open to the possibility of meeting potential partners in the Village, many of them still remain very much open to developing relationships through their interactions with gay men in other 'spaces'. Whilst the participants discussed a variety of spaces (both actual and virtual) they successfully accessed for the purposes of initiating contact with other gay men, I will focus on a number of participants experiences of using public toilets (or as many gay men in the UK refer to them 'cottages') as a form of gay space.

Clive, a participant who identifies as a gay man with learning difficulties, discussed how he had spent over 10 years meeting men for both casual sex and more long-term emotional relationships in cottages. He explained that whilst he had experienced a range of negative reactions in relation to his learning difficulties when spending time in the Village he had never experienced any negative reactions concerning his impairment from the literally hundreds of men he met in cottages. Interestingly, he went on to explain that he had met both his previous partner of six years and his current partner of two years in a public toilet. In addition to Clive's account, a number of the men in the project discussed how they used cottages as a means to meet other gay men; both disabled and non-disabled. It would appear from both the men involved in this project and from similar research (see Cambridge 1997) that there are significant numbers of disabled and non-disabled gay men using cottages to meet other men.

It could be tempting at this point to construct an image of some gay disabled men as having been forced into some form of sexual underworld of toilets, cruising grounds and saunas (bathhouses) in order for them to meet other gay men. However, whilst many of the men would undoubtedly not have encountered cottages had it not been for the disabling reactions they encountered from within the Village, I want to stress that many of the men described their experiences of cottages in very positive terms.

Listening to the men's stories that relate to the use of cottages, it is clear that frequenting cottages represents more than an opportunity to engage in fairly anonymous sex, but also provides these men with a space to enable them to enact a form of resistance to both the heteronormative expectations of society in general but, perhaps more importantly, the hegemonic versions of gay masculinity demanded within the commercial gay scene.

We begin to see an interesting dichotomous relation between cottages and the commercial gay scene in considering a comment made by Baz: "Everyone knows why they're there; you just go with who ever you fancy." For many gay men, both the gay scene and cottages are spaces that facilitate the development of various forms of relationships. However, the divergence between the two spaces centres on the differing regulatory instruments in play in these two environments. We have examined, through the participants' narratives, how the Village presents gay men with a myriad of mechanisms

for regulating who 'belongs' and dictates not only who gets 'membership' but also how 'members' should behave. When we consider cottages as spaces (that some gay men consider gay spaces) it is clear that the 'rules' are very different and in many ways represent an almost binary opposition to the commercial gay scene.

Whilst, the commercial gay scene operates a form of peer surveillance, which not only constructs and regulates the bodily attributes that an individual should aspire to obtain in order to achieve the somewhat mythical bodily form of idealised gay masculinity, it also regulates the type of individuals gay men should be attracted to. A number of the men in the project discussed how they felt that many of the non-disabled men they had sexual encounters with in cottages would not have considered approaching them had they first met in the Village. Whilst the constraints of this project mean that it is not possible to explore if these non-disabled gay men would have indeed approached the disabled participants had they met in the Village, studies specifically exploring gay men's experiences of cottaging have found that many gay men feel far less constrained when they are not within the gaze of the commercial gay scene in relation to the 'type' of men they initiate sexual/romantic contact with (see Flowers, Marriot and Hart 2000).

Carson (2002: 210) provides us with an interesting glimpse into how some non-disabled gay men view their encounters with disabled gay men,

On two or three occasions I have been attracted to young men with learning difficulties because they met the criteria I look for in a young man. On two occasions I had sex with them in a public place... I would never consider developing a long-term relationship with a man with learning difficulties... because I'd be embarrassed to be seen with them in public.

Although the activities of this man may well be disconcerting, it does highlight how some men who use cottages feel that when they are away from a more public gaze, they are free to initiate contact with a wider range of men they find attractive. However, it simultaneously illustrates how these men feel that these relationships are restricted to more covert spaces for fear of being seen to transgress the hegemonic social norms that regulate commercial gay spaces.

The use of cottages by 'othered others' is by no means limited to some disabled gay men. In a recent study exploring the intersection between social class and sexual identity Barrett and Pollack (2005) found that men who self-identified as working-class were less likely to access the commercial gay scene and more likely to meet other gay men through accessing less visible gay spaces such as cottages. Whilst Barrack and Pollock (2005) suggest that there are a number of factors contributing to this, they contend that the images and cultural norms within gay commercial scenes are reflective of those who are freely able to access the scene and that they are not "reflective of all who are homosexually active" (Barrett and Pollack 2005: 438). In many ways, spaces such as cottages, whilst considered by many as the 'seedier' side of gay 'culture', are in fact spaces that many gay men, who either feel they can't or do not want to conform to the requirements of the commercial gay scene, use as spaces to meet other gay men without the pressure to

conform to the idealised hegemonic versions of what a gay man *should* be. Many of the men within the project spoke in ways that differentiated between men that spent time in the Village and men that they met in other gay spaces. It would appear that these experiences are not unique to the men in this project or indeed to disabled gay men in the UK. I want to conclude this section by returning to the message boards of www.bentvoices.org, where one contributor sums up his view of these two different gay 'communities':

I've found that there are two big gay subgroups, (1) mainstream gays, and (2) fringe gays... I've found that fringe gays are more likely to not be bothered by, or in fact downright enjoy, my disability. They can accept me for me. In my experience, mainstream gays tend to find disabled gays invisible, if not downright offensive to their view of perfection.

Concluding Thoughts and Reflections

In this chapter, disabled gay men like Alan, Fred, Eric, Baz, Clive and Henry have provided us with some powerful insights into how, for them, the intersection between sexual identity, disability, masculinity and community is a complex one. Each of these gay men has discussed how they individually negotiate this intersection. Alan has explained how, for him, a form of 'passing' is a strategy that, whilst denying a part of his identity, enables him to spend time in the Village. Fred, through the use of metaphors, described how, for him, the commercial gay scene was not somewhere he felt he would ever meet a partner. Baz and Clive explained how, for them, alternative gay spaces such as cottages enabled them to meet each other and develop a long-term relationship away from the hegemonic regulatory gaze of the Village. For Eric, the attempts from within the Village to enforce a form of gay hegemonic norm upon him has fuelled an ever growing desire to resist these attempts through his pure presence within the Village. As he says "they can all fuck off, I'm here, I'm queer, I ain't going anywhere!"

The men's narratives, have both provided an insight into the complex nature of identifying as male, gay and disabled but also demonstrated how much of the work emanating from both disability studies and masculinity studies does not adequately accommodate many gay disabled men's experiences or account for the multi-faceted dimensions of being considered as 'others' not just by society in general but perhaps more significantly by other gay men. Therefore, I want to end this chapter by returning to where I began with the social model of disability. I have demonstrated that it is possible for those of us researching within the field of disability studies to engage with issues that reflect the lived experiences of disabled people without, inadvertently, invoking the individual or personal tragedy model of disability. Some of the narratives provided by the men in this project have highlighted how issues such as poor self image and a more general form of internalised oppression can be considered as much a result of living in a disabling world as the lack of physical access many disabled people experience. With this in mind, I want to conclude by suggesting that it is not a weakness within the social model of disability that leads to a lack of consideration of the 'private' but rather a weakness in how the social model has traditionally been applied.

CHAPTER 4

Cripsex: Sk(r)ewed Media Representation

Bethany Stevens

Accessible Summary

This chapter discusses how media representation of disabled people affects sexual health. It uses a broad understanding of sexuality, in that it moves away from the idea that sexuality is purely physical and instead connects it to a sense of wellbeing in all aspects of existence, including mind, body and soul. Analysis focuses on two primary ways of representing disabled people: disabled people as pathetic and disabled people as "overcoming" their disabilities. Along with analyzing these dominant ways of representing disability, this chapter looks at how the history of disabled people shapes these two main ways of representing disability. It discusses how disabled people negotiate their sexuality when dealing with social expectations established by media representation. The following are the key ideas in the chapter:

- Media representation leads to social expectations.
- Sexual health is impacted by media representation.
- Disabled people are infrequently represented in the media and when they are it is usually in a negative way.
- Media representation of disability portrays us as either unworthy or exceptional.
- These representations are influenced by the history of eugenics and freak shows.
- Disabled people resist media representation through creating their own media and engaging in performance art.

Introduction

Skewed mainstream media representation of disability in American "screws" disabled people by legitimating sociosexual barriers that exclude and oppress many of us. The power of the media to institutionalize the value (or lack thereof) of people and predilections (J Brown 2002) will be explored in this chapter. While negative sexual assumptions and myths about disabled people pervade media representation in many cultures around the world (Charlton 1998) it is beyond the scope of this book chapter to analyze numerous cultures thus this piece is situated in the cultural context of the United States. Dominant media representations of disabled people enable disability discourse – the institutionalized oppressive understanding of disability. Disability discourse is constituted in media images that are often unrealistic and negative messages – including the representation of disabled people as monstrous, inspirational, undesirable, asexual, dependent, and pitiful (Haller 2000, Ross 1997, Shakespeare *et al.* 1996). As media representation is all too often believed to be a reflection of reality and internalized as truth, disabled people (along with other minority groups) must figure out ways to negotiate these constricting cultural narratives.

Along with interrogating the construction of disability defined and perpetuated by the media, this piece also sets forth a historical analysis of the

underpinnings of dominant disability narratives. In conclusion, examples of positive media representations of disabled people are offered as a harbinger of hope for the transformation of the American cultural imaginary regarding disability. The term 'cripsex' was coined for this chapter to draw attention to the political aspects of the sexuality of disabled people. The rationale of the word 'cripsex' draws on the political nature of the word 'crip' (the shortened and reclaimed form of the derogatory term 'cripple') which signifies a sense of pride in disability by those who utilize it. The word 'sex' is added to 'crip' to draw attention to the political nature of sexuality for disabled people.

The Current State of Cripsex

Disabled people contend with the several negatives stereotypes that affect sexuality. These stereotypes include but are not limited to, the belief that disabled people are asexual, undesirable, not sexually adventurous and have more important issues to worry about aside from sexuality (Silverberg 2003). While issues of life sustainability, such as procuring employment and accessible housing, are imperative to address within the disability community, sexuality should not be believed to be a luxury that only some individuals get to embrace. The hierarchy of needs, which does not place a primacy on sexual (or other forms of social) inclusion, is often espoused by disability advocates and disability service providers. Queer theorist Abby Wilkerson maintains that:

sexual agency must be understood as an important, and in some ways, key component of the liberation struggles of all disenfranchised groups, rather than a luxury to be addressed after achieving goals that might be perceived as more basic (Wilkerson 2002: 37).

This quote is a call to action to incite a revolution of consciousness by conceptualizing cripsex as a central aspect of disability oppression and one deserving social redress.

Cripsex is especially challenging to address because it exists at the crossroads of two issues provoking social anxiety – disability and sexuality. In American culture, it is normative to view sexuality – and talking about sexuality - as anxiety provoking, shame inducing, and even disgusting (Irvine 2002). Similarly, interacting with disabled people and talking about disability provokes social anxiety and distress in many individuals (Goffman 1963, Susman 1994). These anxieties are social products acculturated into Americans through various institutions that perpetuate disability discourse, including the media. The intersection of silence and fear around both sexuality and disability creates a tremendous barrier to catalyzing positive social change in the sexual lives of disabled people.

Without discussing sexuality and disability, those of us who lack sexual access have no way to address these issues. Sexual access entails physical access to spaces that may lead to sexual activity, as well as “psychological, social and cultural contexts and supports that acknowledge, nurture and promote sexuality in general or disabled people’s sexuality specifically” (Shuttleworth and Mona 2002: 3). Part of the support implicated by the preceding statement includes access to communication around sexual needs and issues. As the moniker of the A.I.D.S. activist group ACT UP decries

“silence equals death” (R Smith and Gruenfeld 1998), the silence around cripsex can lead to significant harm. There are countless dehumanizing and abusive acts exacted on disabled people that are met with silence by the media or the criminal justice system (S Cole 1984, Curry and Navarro 2002, Finger 1992, Sherry 2000). In addition, “the ‘code of silence’ has resulted in missed opportunities to use the mass media... to encourage healthy sexual behaviors” (cited in Satcher 2001: 15).

Without cultural acknowledgment of all aspects of our lives, damaging issues like rampant sexual violence and dehumanization continue to persist shrouded in silence. As Mark Sherry asserts:

when we are dehumanized it is easier to justify segregating us in institutions, sterilizing us against our will, forcing us to work for unacceptably low wages and committing crimes against us. In a climate of imposed hopelessness and disenfranchisement, hate crimes flourish (Sherry 2000).

Disabled people have a higher probability of experiencing all violent crimes, with rape and other forms of sexual violence occurring at least two times higher than the general population of America (Finger 1992, Sherry 2000, Waxman 1991a). This is a product of a culture that does not place value on disabled people and instead views us as individuals easily controlled, manipulated and disposed of. The sexual abuse of disabled people draws attention to the sexually schizophrenic nature of American culture – a culture that does not encourage talking about sexuality in a positive manner yet culturally commodifies sexuality in the media. The heightened statistical probability of sexual abuse experienced by disabled people implicates devalued citizenship and reflects a conflict with the stereotype of asexuality, as it suggests that on some level we are sexually desirable.

Being deemed asexual is of the most egregious sexual harms that disabled people contend with because it is a direct assault on our personhood. Harlan Hahn labeled this phenomena “asexual objectification” which is the “assumption that sexuality is inappropriate for disabled people” (cited in Garland Thomson 1997: 25). This incorrect belief that disabled people are not “normal” enough to be sexual is:

a product of the medicalization of disabled people, it is steeped in and reinforces the paternalism that consigns disabled people to a permanent status as children (Charlton 1998: 58).

Popular assumptions and media representation deny the sexuality of disabled people “loudly, repeatedly and not silently” (Kafer 2003: 85). The consistent representation of disabled people as asexual provides a powerful tool to legitimate inhumane treatment and reinforces the idea that disabled people lack agency or control over our lives (Waxman 1991a). The myth of asexuality and paternalism are bound together as products of unequal power relations between disabled and non-disabled people.

Sexual stereotypes shape the social conception of individuals because they have the power to undercut a foundational aspect of personhood –

sexuality. Co-founder and former president of Sex Information and Education Council of the United States (SIECUS) Mary Calderone stated:

sexuality means everything that you are, that you were born with, that you experienced, that you thought about, that happened to you, that related to you being a sexual person” (cited in Irvine 2002, p. 31).

Calderone’s quote draws attention to the sociopolitical nature of sexuality by underscoring the fact that the meanings of sexuality are a product of innate personal qualities as well as socially constituted realities. Acculturation of negative sexual values – such as being deemed deviant or otherwise unworthy - has historically been used to constrain the political and social agency of various groups of marginalized people, such as disabled, queer, Black and female individuals (Wilkerson 2002). These negative values are imposed on and often internalized by marginalized people causing deleterious effects on sexual health.

The holistic understanding of sexuality has in recent years been framed as sexual health by leading organizations such as the World Health Organization, the Centers for Disease Control and Prevention and the Office of the Surgeon General of the United States (Centers for Disease Control and Prevention 2008, Satcher 2001, World Health Organisation 2006). Sexual health is defined as:

a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled (World Health Organisation 2006: 5).

This definition recognizes that disparities in sexual health are largely a consequence of the presence of oppressive social forces, such as discrimination and coercion.

The recognition of the need for sexual health for disabled people is a sociopolitical issue deserving public attention and intervention. It is crucial that people recognize that social issues, including sexual access, cannot be sacrificed in the honor of dealing with economic issues, even if they seem more pressing to rectify. For many disabled people, including myself, the social aspects of disability oppression are often much more oppressive in our daily lives than physical and economic barriers (Linton 1998). While it is challenging to discuss and attempt to change the issues that are deemed private and difficult to legislate – such as sexual and social exclusion – it is important that the conversation about these issues continues to provide a space to stimulate amelioration. If cripsex was valorized, our humanity would be validated.

Media Discourse Shapes Sexual Subjectivities

Media creates discourse by institutionalizing hierarchies of embodiment and predilections. The construction and perpetuation of discourse through media represents discursive sociopolitics at work, in which individuals are taught how to respond to various issues and identities (Irvine 2002). The role of the media as an emotional coach comes to fruition by teaching “feeling rules” – the social guidelines or scripts that define the emotional tone and expectations of a situation (cited in Irvine 2002, p. 144). By understanding that emotions are products of socially produced discourse, the fictional and malleable nature of discourse is exposed. As Michel Foucault asserts “discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it” (1978). Therefore, while it is important to recognize that media discourse constructs social barriers to accessing a positive self-conception and identity, media also can offer a space for revolution by challenging what is valued culturally.

Media discourse is a cultural construct that constitutes a version of reality that marginalizes many, if not most, Americans. This marginalization process occurs through constructing a very narrow conception of valued embodiment and the use of strategies that flatten the lived experiences of minorities into unrealistic stereotypes (J Brown 2002). Often these stereotypes rely on animus driven antiquated versions of personhood, such as the mammy or sexually ravenous representations of African-American women (Dwight and Hebert 2006). As feminist scholar bell hooks argues, the narratives about but not by African-Americans:

determines how blackness and people are seen and how other groups will respond to [African-Americans] based on their relation to these constructed images” (cited in Dwight & Hébert 2006: 299).

The same is true for disabled people, as the images that pervade American culture provide a social script for the treatment of disabled people as deserving of pity or adoration for basic human feats (Haller 2000). As stereotypes are often internalized creating self-fulfilling prophecies, a person who is represented as pitiful or sexually abnormal may believe that they deserve dehumanizing treatment. In that way, stereotypes serve as more than just rhetorical and representational methods to sell media; they also reflect and distort reality for many individuals – including those represented.

Body image standards are partially constructed through media representation and impact sexual agency negatively when the standards are not met. Media portrayals of women socially constrict the understanding of beauty within a Eurocentric anorexic model (Boston Women’s Health Book Collective 2005, Sekayi 2003). The idealization of thin embodiment has increased significantly in the past twenty-five years ago, as “the average fashion model was 8% thinner than the average woman [in the 1980s]...today, that number has risen to 23%” (Derenne and Beresin 2006). An excellent example of the power in media shaping bodily value is noted in a study in Fiji analyzing body image of individuals before and after the introduction of television. Prior to television arriving on the island, most Fijians were happy in different sized bodies and larger bodies signified familial prosperity. After the introduction of television in

1995, dieting and eating disorders skyrocketed from 0 per cent to 69 per cent (Derenne and Beresin 2006). This example elucidates the power of the media to shape idealized standards of beauty.

Few people can or should live up to this unhealthy standard of beauty promoted by the media, but this standard is especially unattainable for those of us who fall outside the white, non-disabled, symmetrical standard of valued embodiment. The unrealistic standard of beauty creates a significant issue for women, as their value is often assessed of women based on the ability to live up to the normative standard of beauty (Boston Women's Health Book Collective 2005). Female minorities experience a form of double oppression as they exist at the confluence of the devalued meanings of a minority classification and gender (Dwight and Hebert 2006, Garland Thomson 1997, Shakespeare *et al.* 1996). Being a member of a minority group is often a barrier to accessing normative beauty because that which is deemed beautiful is raced, abled and gendered. To compound that barrier with gender requirements creates an especially oppressive social position for women of minority groups. The focus on the impact of idealized beauty on women is not intended to exclude men from the oppressive force of media shaping the value in embodiment. Media representation offers body pedagogy regarding worthy types of male bodies and how masculinity should be performed (Dwight and Hebert 2006). Special attention is given to women because men are often given more social latitude to be judged by other aspects of their personhood, like their intellectual capacity and power, rather than solely focusing on their bodies.

Media representations extol the virtue of normative embodiment by portraying how bodies should appear and move. Physical impairments violate the "grammar of embodiment" extolled by media, as disabled bodies break the rules of normativity (Garland Thomson 1997). Interestingly, without deviant disabled bodies to violate the grammar of embodiment, normative embodiment would not exist. As Garland Thomson (1997) asserts, disabled bodies provide the contours of normate bodies. 'Normate' operates in the same manner as the word 'normative' by calling attention to the socially constructed nature of the word 'normal' while simultaneously mocking normativity (Garland Thomson 1997). The media helps promulgate the value of normates in American culture by underrepresenting diversity in embodiment. This is noted in that fact that while 20 per cent of Americans between the ages of 5 and 64 are living with a disability, less than 2 per cent of characters on television are disabled (Raynor and Hayward 2005). Through institutionalizing normalcy in embodiment, social inequalities are exacted upon disabled people, as well as other social deviants (L Davis 1995).

Not only does the construct of the normate help legitimize disability oppression, it also perpetuates the institution of compulsory able-bodiedness. Similar to the way Adrienne Rich (1980) explained heterosexuality is an institution in which heterosexuality is exalted as the norm for all people, Robert McRuer (2002) asserts that able-bodiedness is also an institution. McRuer wrote that American culture "assumes in advance that we all agree: able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for" (2002: 93). This assertion is supported with a brief analysis of a few commercially successful films in recent years that used disability as a major theme. *Million Dollar Baby* (Eastwood 2004) and *the Sea*

Inside (Amenábar 2004) feature individuals who acquire disabilities and find that their remedy is suicide. Several protests were hosted around the nation to speak out against these films as they support the assertion that disabled bodies should not exist and are worthy of death (McRuer 2006b). This belief that one is better dead than disabled is a product of the institution of compulsory able-bodiedness.

Dominant Disability Media Narratives

British sociologist Colin Barnes (1992a) created a taxonomy of ten disability stereotypes in media representation. Barnes (1992) asserts that common media representations of disabled people depict us as: 1) pitiable and pathetic, 2) objects of violence, 3) objects of ridicule, 4) our own worst and only enemy, 5) a burden, 6) sexually abnormal, 7) incapable of participating fully in community life, 8) sinister and evil, 9) atmosphere or curio and 10) as super cripples. While I agree with his assessment, I have condensed these stereotypes into two main narratives – the ‘supercrip’ and the ‘pathetic crip’ – as they serve as conceptual umbrellas for the stereotypes listed. The ‘pathetic crip’ narrative is comprised of stereotypes 1-7 as ‘pathetic crips’ are often depicted as: pitiable, objects of violence and ridicule, our own worst enemies, a burden, sexually abnormal and incapable of full community participation. It is striking that the majority of our stereotypes include a lack of personal agency. The ‘supercrip’ narrative includes stereotypes 8-10 as disabled people are portrayed as individuals who are valued for their power to overcome their disability; being either heroic or malevolent ‘supercrips’ and providing contextual depth to a story.

Both the ‘supercrip’ and the ‘pathetic crip’ narratives operate by conjuring the emotion of pity. While pity is often framed as a valorous emotion that encourages mercy or aid for the pitied, it is important to note that pity supports and legitimates unequal social relations. As philosopher-crip Joe Stramondo aptly points out in his forthcoming piece, "How Pity Is a Social Harm to People with Disabilities" in *Social Philosophy Today: The Public and the Private in the 21st Century*, Jean-Paul Satre (1948) states pity is an emotion that exists only when one group has more social power than the other. Pity can never just be a positive emotion in which an individual attempts to commiserate with or help their fellow human; instead it is an emotion that demarcates boundaries between valued and devalued persons. Pity sets disability apart from the response to many other minority groups, such as queer people and people of color, as it creates a veil of benevolence concealing feelings of discomfort and even hatred. This method of concealing negative emotive responses to disabled embodiment creates a significant barrier for those interested in changing the social status of disability because it is difficult to convince individuals they are oppressing others when they believe they are engaging in a meritorious act.

The ‘supercrip’ narrative uses covert pity – in which psychological distance between the normate and the disabled person is created by constructing us as inspirational yet a person that no one really wants to be. Media scholar John Clogston defines ‘supercrips’ as disabled people portrayed as deviant because of ‘superhuman’ feats (i.e. an ocean-sailing blind man) or as ‘special’ because they live regular lives ‘in spite of’ disability (i.e. a deaf high school student who plays softball). This portrayal reinforces

the idea that disabled people are deviant -- and so, for someone who is less than 'complete,' the accomplishment is 'amazing' .

Most disabled people do not aspire to inspire people; instead most of us just want to live. Like many of my disabled comrades, I am often told how inspiring I am and since I have started identifying as a sexuality scholar, I have begun to subversively retort that "I shouldn't inspire you because I get out of bed in the morning but I hope I inspire you to have good sex".

The 'pathetic crip' narrative draws on pity in an overt manner – utilizing words such as 'victim' and 'suffering' to openly encourage the feeling of pity within the audience (Haller, Dorries and Rahn 2006). Telethons and poster children used to raise money for poor 'pathetic crips' are the best contemporary examples of the use of pity to frame disability in the media. Disabled people are vocal in their protest against telethons, as they support our infantilization and commodification (C Barnes 1992a). Through the years protests against the Muscular Dystrophy Association (MDA) telethons have erupted in Los Angeles, Chicago, Denver, New York, and Charleston, South Carolina (Johnson no date). Harriet McBryde Johnson holds the record for endurance in protesting against MDA for 14 years and explained in her autobiography *Too Late to Die Young*:

I don't like the way the telethon depicts disabled people, including muscle diseases like I have. It's all about stirring up pity, when we don't want pity. And Jerry Lewis ought to be fired. He actually called people in wheelchairs 'half persons' (Johnson 2005: 48).

Host of the MDA telethons, Jerry Lewis, claimed on CBS Sunday Morning that those protesting against his work were analogous to Nazi storm troopers and asserted: "Pity? You don't want to be pitied for being a cripple in a wheelchair? Stay in your house" (cited in Johnson, no date).

The rhetorical strategies employed to construct both the 'supercrip' and the 'pathetic crip' support the understanding of disability within a depoliticized and medicalized framework. The medicalization of disability entails a focus on the disabled body as diseased and needing surgical as well as other forms of medical intervention to create a "normal" body (Oliver 1990).

The medicalization of disability is reified by centering narratives on the individual who can 'overcome' or by saved from their impairment; with overcoming disability making the individual happier and more whole (Haller 2000). Both the 'supercrip' and the 'pathetic crip' narratives place emphasis on the individual rather than interrogating and ameliorating social structures that oppress disabled people. The 'supercrip' narrative validates disability oppression by placing the onus of success on the disabled person. This narrative also depoliticizes disability through representing 'supercrips' as those who overcome disabling aspects of their lives without social support or modification of their environment. The 'pathetic crip' narrative posits that money can be the savior for the otherwise worthless lives of disabled people. This narrative depoliticizes disability by shoring up the belief that disabled people are not a political group worthy of social inclusion, aside from in a charitable mode. By focusing on the individual with a disability, rather than the social issues of disability, substantive issues of disablement are silenced to commodify disability in the media.

History Imbued in Media Narratives

Through history cultural fictions are constructed that determine the social meaning and value of aspects of identities, such as gender, race and ability (J Butler 1993, P Collins 2005, Garland Thomson 1997). Media representation is often a direct reflection of culturally constructed fictions, as stereotypes often rely extensively on promoting flattened inaccurate portrayals of socially devalued citizens. The two disability narratives I have offered, the 'supercrip' and the 'pathetic crip,' are imbued with two components of the history of disability in America. The history of freak shows helps provide the historical foundation for the 'supercrip' narrative and eugenics influences the construction of the 'pathetic crip.'

Freak Shows Imbued in 'Supercrip' Narrative

Freak shows held a prominent role in the entertainment of Americans from 1840 to 1940 (Garland Thomson 1996). Robert Bogdan (1996) explains the taxonomy of freaks as "born freaks" (those with congenital physical anomalies, such as aesthetic or physical impairments), "made freaks" (those who do something unusual, such as tattoo the body extensively) and "novelty acts" (those who engage in a performance, such as sword swallowing). Eli Clare (1999) adds to this taxonomy by asserting that the "born freaks" were often individuals who were racialized others and often victims of colonialism. Clare asserts that freak shows told a "story of an elaborate and calculated social construction that utilized performance and fabrication as well as deeply held cultural beliefs" such as racism, ablism and ethnocentrism (1999: 71). Freak shows:

simultaneously reinscribed gender, race, sexual aberrance, ethnicity, and disability as inextricable yet particular exclusionary systems legitimated by bodily variation... [making] a freak of nature... a freak of culture" (Garland Thomson 1996: 10).

The objectified othered bodies were presented as void of personhood and possessed market value even after death (Garland Thomson 1997).

A pseudo scientific and educational rationale was deployed by the hosts of freak shows in order to provide legitimacy in a purely capitalist enterprise (Bogdan 1996). The pseudo scientific and educational framework encouraged audience members to visually dissect the freaks on stage as if they were specimens (Garland Thomson 1997). This intent was reinforced through physical staging, with the freak spatially segregated either by being elevated on a stage or behind a barrier. The visual segregation of the freak from the normate audience provided psychological distance between the two to enhance the othering process. The psychological and physical distance between the normate and the freak provided encouragement to view the freak as a platform on to which the normate audience members could displace their anxieties concerning the fallibility of their bodies. As the normate is defined in relation to the disabled body, freaks represented an opportunity "to formulate the self in terms of what it was not" (Garland Thomson 1997: 59). The framing of freaks endorsed a dominant normative identity as both a personal and a national goal (Garland Thomson 1996).

The encouragement to value sameness in bodies is tied to the expansion of industrialization, occurring during the time of freak show popularity. Industrialization and its machine culture thrived on factory work that required bodies to operate with regularity and efficiency (Garland Thomson 1996). Freak shows offered a way to consolidate selfhood that was “capable, rational and normative... [as well as striving] toward an ontological sameness upon which the [notions] of democratic equality” and capitalism are predicated (Garland Thomson 1997). Interestingly, freak shows and the word ‘normal’ came to fruition during the same period in American history – around 1840 (L Davis 1995). This speaks to the zeitgeist of America culture as it responded to the capitalist need to regulate bodies.

The history of freak shows influences the narrative of the ‘supercrip.’ Freak discourse is imbued in the narrative of the ‘supercrip,’ as born freaks were valued for engaging in mundane activities, such as playing the piano, or simply sitting on stage (Larsen and Haller 2002). The same is true for many ‘supercrips’ as they share exaltation for simply living or engaging in a spectrum of activities despite being in devalued bodies (Haller 2000). Freaks and ‘supercrips’ share a common rhetorical strategy; both attempt to inspire the normate to feel better about their body in relation to the ‘Other’. The rationale of commodification of freaks persists today. This reasoning places value on the disabled body through commodification and segregation, best noted in institutionalization. Over 2 million individuals with disabilities are warehoused in institutions (She and Stapleton 2006). Disabled people are worth more to the Gross National Product within institutions than in their homes because of the expensive services provided to them (Russell 1998) and the powerful lobbyists protecting service interests. This segregationist and capitalist practice reifies the value of disabled people as non-agentive; we are only commodities for others to turn a profit on.

Eugenics Imbued in ‘Pathetic Crip’ Narrative

The history of eugenics provides the foundation for the ‘pathetic crip narrative.’ Eugenics is a social philosophy that advocates for the improvement of humanity through various forms of intervention, such as sterilization and homicide of devalued individuals (Osborn 1937). Although constructed within the historical imaginary of America as a misdeed committed only by Nazis in Germany, eugenics experienced prosperity in American until the 1970s (Lombardo 1985). The American legislation for compulsory sterilization of ‘degenerates’ – including intellectually and/or physically disabled people; especially those of color – existed nearly a decade before the Nazis started 4 Tiergartenstraße and served as its model (Black 2003). These two historic examples that follow are chosen strategically to help locate eugenic ideology within the purview of the America.

The Supreme Court in *Buck v. Bell* (1927) held eugenic policy as constitutional and heralded it as a method to rid America of defective disabled people. The case centered on a young woman, Carrie Buck, who was believed to lack full mental capacity and embraced sexually promiscuous ways (Lombardo 1985). Follower of eugenic philosophy and then Chief Justice of the Supreme Court Oliver Wendell Holmes, Jr. (1927) wrote:

It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough (p. 207).

While it is now unconstitutional to forcibly sterilize criminals, it is still held constitutional to forcibly sterilize disabled people.

This historic *Buck* case should be viewed in the “legal hall of shame because it was built on a mountain of intentional inaccuracies” that helped successfully push this policy through the American court system (cited in Vergano 2008). An examination of the court records, by legal historian Paul Lombardo, finds that “scientists and lawyers, including Carrie Buck’s defense attorney, conspired against her” to promulgate sterilization legislation (Lombardo 1985, Vergano 2008). He also revealed that the Bucks were not imbeciles, as “Carrie was an average student and [Carrie’s daughter] Vivian...made the honor roll once in her short life” (Vergano 2008). The historic record around *Buck* places in question whether justice was served in this case.

While there currently is no legislation compelling sterilization in America, there was a recent episode of ethical and legal sterilization of a young girl with a disability (MSNBC 2006). The “Ashley X treatment” was used in 2004 on a significantly mobility and cognitively impaired young girl. “Ashley” was forcibly sterilized through the removal of her breast buds and uterus, as well as placing her on a regimen of high doses of estrogen (Gunther and Diekema 2006). The doctors involved in the case argued that the rationale for such a treatment was to achieve:

permanent growth attenuation while the child is still young and of manageable size [the procedure] would remove one of the major obstacles to family care and might extend the time that parents with the ability, resources, and inclination to care for their child at home might be able to do so (MSNBC 2006).

The pediatricians involved in the case also removed her appendix, in the off chance that she experienced appendicitis and could not report it; appendicitis occurring sporadically in about 10 per cent of the population (Gunther and Diekema 2006).

Instead of addressing the pervasiveness of sexual abuse of disabled people, the doctors rendering the “Ashley X treatment” stripped Ashley of her sexual capacity and agency. Several disability rights organizations, including Feminist Response in Disability Activism (FRIDA), ADAPT and Not Dead Yet, protested the support of the “Ashley X treatment” at American Medical Association (AMA) building in Chicago. The outcry won them a meeting with AMA Chief Executive Officer Dr. Michael Maves and three other AMA officials (Smock 2007). Maves wrote a letter to the members of FRIDA claiming “that the AMA currently has no official policy on the treatments outlined” in the Gunther & Diekema article (cited in Smock 2007). While the Washington state hospital that housed the procedure and Dr. Daniel Gunther, initially defended

their decision to perform the surgeries on Ashley in May of 2007 they publicly denounced their claim saying they made a mistake (Alexander 2007).

The sterilization of Buck and Ashley serve as examples of American culture embracing eugenic policies as a way to deal with the 'problem of disability'. This sort of view of disability is imbued in the 'pathetic crip' narrative. The 'pathetic crip' narrative, best captured in telethons, posits disabled people as useless drains on the government and burdens on their families. Building on the Nazi phrase for disabled people 'useless eaters' (Mostert 2002), I maintain that 'pathetic crips' are framed as useless eaters and useless breeders. Like the 'supercrip' narrative the 'pathetic crip' narrative reinforces inhumane treatment of disabled people, legitimates sterilization of disabled people, and supports the viewing of disabled bodies as lacking value (Waxman 1991a).

Negotiating Narratives

Disabled people must negotiate oppressive and inaccurate narratives that pervade American media and culture. These narratives create a paradoxical position for disabled people, as we occupy a space of both social hypervisibility and emotional invisibility (Zitzelsberger 2005). This suggests that the 'supercrip' and the 'pathetic crip' narratives do not operate in isolation or on separate trajectories. Instead these narratives are woven together to help define cultural imagery and discourse about the lived experiences of disabled people.

The 'supercrip' narrative promotes the hypervisibility of disability by encouraging the visual dissection and devaluation of our bodies based on standards of normative aesthetics. Disabled performance artist scholar Petra Kuppers (2003) explains the process of hypervisibility as being defined solely by physicality and immediately categorized based on corporeality. The lived experience of hypervisibility is best noted by visually apparent disabled people experiencing stares by normates; in which the normate visually dissects the body and seems to assess value based on the produce of the gaze. The stare, like the expression of pity, expresses an "absolute state of difference" and manifests an unequal power relation between normates and disabled persons (Garland Thomson 2002) Like the majority of my fellow disabled comrades, I experience stares daily. It is often exhausting to try to deflect this daily reminder of difference.

The 'pathetic crip' narrative supports emotional invisibility of disabled people. The feeling of being emotionally invisible is best noted in sociosexual exclusion and infantilization (Zitzelsberger 2005). When normates engage in shunning disabled people in social settings they are engaging in a process that can lead to eugenics (i.e. social segregation to prevent and/or prohibit sexual interaction), as they are implicitly expressing that the disabled person is undesirable because they are a non-meritorious breeder. The devaluation and infantilization of disabled people helps support the necessity of measures, like institutionalization and other agency stripping acts of state violence (Waxman 1991a).

As a visually apparent disabled woman, I negotiate the paradoxical social position of hypervisibility and invisibility. For years I believed media portrayals concerning valued embodiment, as I internalized unrealistic standards of beauty and normalcy deemed as valued in the media. I continue

to fall short of these ideals, as do most people. Going through years of cringing at my own reflection in the mirror is such a waste of humanity and sadly, I know my feelings do not exist in isolation (Zitzelsberger 2005). It took finding disability activism and disability culture to restructure my view of disability and it is my hope that with work like that presented in this anthology, disabled people can see that we do not have to conform to disability discourse and can embrace beauty despite what culture attempts to institutionalize in us all.

Whispers of a Cripsex Revolution

Whispers of a cripsex revolution in the media provide hope that negative disability discourse can be resisted. The concept of the whisper providing hope of social change comes from the research of feminist scholar Michelle Fine. Fine (1988) analyzed sexual education in American public schools finding pervading narratives of female victimization and sexual danger. Despite the negative messages being taught by teachers about sexuality, Fine (1988) reported hearing whispers of desire echoed by the girls. These whispers manifested as girls wanting to be sexually satisfied and not wanting to be confined in relationships (Fine 1988). The same recognition of undertones of change exists in media representation of disability. The whisper of revolutionary cripsex representation is noted by publicly embracing of humanity and sexual desires.

In recent years there have been positive media representations of disabled people, providing alternative discourses to the negative narratives presented by mainstream American media. *Sins Invalid* is leading the way by providing positive representations of cripsex by disseminating erotic art. *Sins Invalid* is a performance art collective hosted to explore cripsex in a frank and often transgressive manner. The collective comes together annually in San Francisco to provide an “unashamed claim to beauty in the face of invisibility” (Sins Invalid 2008). The performances range from spoken word to sadomasochistic scenes. Director of National Outreach at the National Sexuality Resource Center Joy O’Donnell stated:

Sins Invalid has already begun revolutionizing the way all Americans relate to their own abilities around sexuality and we cannot wait to see the transformative impact that will have as the production grows nationally” (Sins Invalid 2008).

More information about *Sins Invalid* and video clips from past performances can be found at sinsinvalid.org.

The majority of the films featuring overt representations of cripsex are relatively obscure and difficult to procure. Appendix 1 provides a list of cripsex films, compiled with several scholar-activists, including Lawrence Carter-Long. *Murderball* (H A Rubin and Shapiro 2005) stands out as the most commercially successful. While the film about the lives of quad rugby players touted hegemonic masculinity and heteronormative social scripts, it included an excellent 10-15 minute discussion about sexuality. In the discussion, a few of the quad rugby players explained their negotiation of sexual activities after acquiring spinal cord injuries. They mentioned issues with achieving and sustaining erections, as well as their capacity to have fulfilling sexual lives.

Their honesty and sex appeal was reinforced by their female lovers adoringly embracing and talking about them throughout the film.

Aside from the fifteen films listed in the appendix (and compiled by several disabled scholar-activists, including Lawrence Carter-Long), few representations of cripsex can be found. There are scant erotic websites made by disabled people depicting our sexuality, such as *Gimps Gone Wild* (GGW) and *Disabled Erotica*. The websites mentioned are excellent examples of representations of the sexual agency of disabled people and thereby offer a powerful tool to resist our sexual exclusion and segregation. In March of 2009, a law was proposed in Massachusetts that would make these websites and any other form of erotic representation featuring disabled or elderly people a crime analogous to the possession of child pornography (Wedge 2009). This proposed law is based on the principle of benevolence, as it seeks to protect us from 'perverts' preying upon our vulnerable nature. The truly disturbing aspect of this law is that it would prohibit disabled and elderly people from *choosing* whether they would want to be represented erotically. Sex educator and author of the *Ultimate Guide to Sex and Disability* Cory Silverberg states that:

there's a long history of sexual material featuring people with disabilities being treated differently both in the eyes of the law and of the general public. My first encounter with this was when Annie Sprinkle was arrested for a series of photos she took with fellow adult performer Long Jean Silver who is an amputee. The images were considered obscene not solely because they were sexual, but because one of the people in the pictures was visibly disabled. The same photo shoot minus the absent limb would have been fine (Silverberg 2009).

While erotic representation is a contentious issue for many, disabled people should have the right to this kind of representation like adult normates.

These examples should inform policy change within the media in order to more accurately reflect the lived experiences of disabled people, not rely on outdated cultural stereotypes like the 'supercrip' and the 'pathetic crip.' Diversity in images of disabled people needs to be available publicly, including erotic images, in order to counter these powerful narratives that constrict the lives of disabled people. British performer Mat Fraser states:

"It is the erotic that helps us to feel alive, real, included, and disabled people have so much to offer the world of the erotic and the adult" (Adams-Spink 2009).

His statement echoes feminist scholar Audre Lourde's (1984) belief that the erotic has the power to replenish the spirit in the face of oppression. There is power in politicizing our pleasure and disseminating representations of all aspects of our lives. Disabled sexual activist Barbara Waxman (1991b) articulated the importance of embracing the nuances and beauty in cripsex when she wrote:

To realize our sexual freedom, our goal must be to infuse the dominant sexual culture with the richness of our own experience. We must

celebrate our differences from those without disabilities. We must see that our differences in appearance and function which are the sources of our degradation also contain the seeds of our sexual liberation.

One way to do just as Waxman recommends in her statement is to work to infuse our images into mainstream media. The *I AM PWD* campaign works to that end by increasing “visibility and equal employment opportunities for actors, broadcasters and sound recording artists with disabilities throughout the entertainment and news media” (I AM PWD 2008). *I AM PWD* speaks to just the sort of revolution needed in media representation to change the cultural meaning of cripsex. It is crucial that those interested in disability or social justice issues help support inclusive media, as well as other aspects of inclusive culture, as we all possess the capacity to help shape the value of people.

Appendix 1

- 1) *And contact is made* - American, unknown – documentary featuring the lives of disabled men
- 2) *Sex and the handicapped* - Swedish, 1973 – documentary profiling the role of health care providers and educators in aiding the sexual lives of people with disabilities
- 3) *Sex therapy for the quadriplegic couple* – American, 1979 – documentary featuring the sexual interaction of a quadriplegic couple facilitated by sex therapists
- 4) *Active Partners* – American, 1979 – documentary with quadriplegic male pleasing his nondisabled lover
- 5) *Sara Needham: A very special person* – American, 1981 – profile of the sexual life of a woman without a few limbs
- 6) *Tell them I'm a mermaid* – American, 1983 – Victoria Lewis' troupe of women with disabilities discuss their sexualities and other aspects of their identities
- 7) *La Joie* – French, 1996 – black comedy about the sex life of a French man with CP
- 8) *Sick: The Life and Death of Bob Flanagan, Supermasochist* – American, 1997 – documentary about the BDSM activities of Bob Flanagan, as well as his experience living with cystic fibrosis
- 9) *Sex & Cerebral Palsy* – Canadian, 2000 - Linda Feesey documents conversations and sexual encounters of two disabled couples
- 10) *Keeping It Real: The Adventures of Greg Walloch* - American, 2001 – documentary of a disabled and gay comedian Greg Walloch discussing his life and sexuality
- 11) *Murderball* – American, 2005 – documentary about the lives of quad rugby players
- 12) *The Crippendales* – British, 2006 – documentary profiling an all disabled male stripper troupe
- 13) *Forbidden Acts* – American, 2006 - features the sexually themed poetry by Leroy Moore
- 14) *Want* – Canadian, 2007 - Loree Erikson explores her sex life and discrimination against the sexual lives of people with disabilities in this hot film
- 15) *It is Fine! Everything is Fine* – American, 2007 – trilogy of films featuring the psycho-sexual fantasies of man with CP

CHAPTER 5

Exploring the Barriers to Sex and Relationships for People with Learning Difficulties

Ruth Garbutt

Accessible summary

This chapter talks about people with learning difficulties and sex and relationships. It shows how people with learning difficulties have been treated badly in the past. People with learning difficulties were put in institutions so that they could not have relationships or sex. We have done some research and found that people with learning difficulties still come across difficulties in the area of sex and relationships. These are the things we found out:

- There are not many places for people with learning difficulties to meet.
- Parents can be protective.
- Professionals can be unhelpful.
- There is not much accessible information.
- People from different religions have different views on sex and relationships and professionals do not always know about these views.
- There is very little sex education for people with learning difficulties.
- Teachers and other professionals don't get much training in sex and relationships.
- Parents want to meet together more so they can help each other out.
- Some people with learning difficulties have difficulties in understanding things. Sex education needs to be better so that people with learning difficulties can understand it.
- Some people with learning difficulties have difficulties in communicating. People who teach sex education need to work out the best way to work with people who find it difficult to communicate.
- Professionals need to be aware of all these things.

People with learning difficulties sometimes do not get to do things that everyone else does. This can be called social exclusion. People with learning difficulties sometimes don't get a chance to have jobs. We have found that people with learning difficulties sometimes don't get a chance to have sex and be in relationships. We want to tell people that social exclusion is not just about jobs. It is also about other things as well, like relationships.

Introduction

Since the awareness of AIDS in the UK in the 1980s and the subsequent media campaigns to reduce the incidence of sexually transmitted diseases, issues around sex and sex education have been high on the government agenda (Berridge 1996, Berridge and Strong 1991, Weeks 1988). Despite these campaigns, and increasingly explicit sexualised images in the media, as a society, 'sex' is still often seen as 'taboo'. Deacon (2007: 1), states:

Sex is, by definition, the most natural thing in the world. Yet it remains a subject that we're not at ease with as a society...

Shakespeare et al (1996: 19) furthers Deacon's posit by suggesting that '...the subject of sexuality and disability is still largely a taboo area'. This chapter explores the taboo of sex within the context of the experience of people with learning difficulties. It will look at the way in which people with learning difficulties have to contend with a myriad of barriers in relation to sex and relationships. The chapter will draw on a case study of the 'Sex and Relationships' research project, to show how the barriers faced by people with learning difficulties all contribute to wider conceptual frameworks of social exclusion.

Historical context

Historically, before the introduction of Community Care policies in the UK in the 1990s, a large number of people with disabilities lived in institutions, and were often segregated (Potts and Fido 1991, Sinson 1995, Welshman and Walmsley 2006). Within these institutions, the potential of the residents to have relationships were very limited. Vernon (1995: 22) talks about his memories of living in Combe Farm, a Spastic Society residential centre:

In those days, the Spastic Society could not cope with the idea that disabled couples had the same needs and desires as everyone else. Marriage was out of the question. We were allowed to get engaged, but that was all... The men slept in their dormitories and the women in theirs. Any sexual activity just wasn't allowed.

During the Eugenics movement, particularly in the late nineteenth and early twentieth century, attitudes focused on the discouragement of the procreation of people with learning difficulties in order to prevent what was seen as their 'defective' genetic material being passed on and endangering the human race (Barker 1983, Blacker 1950). In 1896 the National Association for the Care and Control of the Feeble Minded [*sic*] was set up, with its aim of segregating people with learning difficulties and preventing their sexuality and reproduction. This was motivated by:

middle-class fears about working class fertility, greatly fuelled by the Eugenics Movement's scaremongering about the likely decline in the talents of British people (Ryan and Thomas 1987a: 107).

The Eugenics movement was driven by the desire for society to accept the 'social responsibility' of improving the human gene pool, in order to create healthier and more intelligent people, to save resources, and 'lessen human suffering' (de la Cruz and LaVeck 1973). As such, the prevention of pregnancy was high on the agenda, and contraception could take various forms. Sexual relationships were discouraged and many women with learning difficulties were sterilized (Howard and Hendy 2004). Goodman, writing in the 1970s, talks about institutional living being used as a form of contraception:

The issue first arose over the question of whether an adolescent girl, who was having intercourse, should be fitted with a contraceptive device or placed in an institution as a mode of contraception (Goodman 1973: 79).

Another writer states that gay relationships were also seen as a method of contraception: “One of the commonest forms of contraception among those who are institutionalised...is homosexuality...” (Breg 1973: 107).

Within the last century, there have been immense changes in services for people with learning difficulties, with the provision of education, residential and day services. With the implementation of Community Care policies in the 1990s, many people with learning difficulties were moved out of institutional living and into the community. There is presently now less segregation between the sexes and less control over relationships. Within the UK, legislation, such as The Human Rights Act (1998, Article 8), the Disability Discrimination Act (1995) and the Mental Capacity Act (2005), all support the rights of people with learning difficulties to have fulfilling relationships and sex lives if that is their choice. Although explicit eugenic attitudes are now rarely openly expressed, eugenic principles and practices can still be seen through the practice of aborting unborn fetuses that have been tested as having certain abnormalities. Invariably, attitudes that have arisen out of a historical legacy of discriminating practices, can also take time to change.

The historical context around sexuality, therefore, defines the extent of the problem that people with learning difficulties have faced. Even though, in the twenty-first century in the UK, many people with learning difficulties are living, working and taking their leisure with everyone else in the community, addressing the barriers caused by a historical legacy can be very difficult. Shakespeare et al (1996: 200) states: Centuries of treatment as second class citizens, viewed by the rest of society as pathetic, tragic, brave or monstrous and predatory, will not be overturned overnight.

The following table (*Table 1*) summarises the historical context and its possible solutions:

Table 1: The historical context of sex and relationships for people with learning difficulties and its possible solutions.

Barrier	Possible solution
Institutional living	Closure of institutions may result in long-term improvement in attitudes and practices
Segregated (male/female) services	Reduction of segregated services may result in long-term improvement in attitudes and practices and in more opportunities for people with learning difficulties to have relationships.
Eugenics movement	Reduction in sterilization of women with learning difficulties may improve the lives of people with learning difficulties and change attitudes. The application of rights-based legislation over time may improve attitudes and give people with learning difficulties more power to challenge discriminatory practices.

The Sex and Relationships project

The Sex and Relationships research project arose out of the recognition that people with learning difficulties have historically had their sexual and relationships needs ignored or denied. The Sex and Relationship project is a three-year piece of research being undertaken by CHANGE, a national organisation that fights for the equal rights of people with a learning difficulty, in partnership with the Centre for Disability Studies at Leeds University. The project came about because, in previous work, CHANGE found that many people with learning difficulties said that they were never told about sex and relationships when they were younger. The people with learning difficulties who were in contact with CHANGE said that if they had had better sex education, they might have made different choices as adults. Literature has also indicated that this is a key area for research (eg: Barber and Redfern 1997, Cambridge 1999, Dent, Vergnaud and Piachaud 1994, Lindsay, Michie, Staines, Bellshaw and Culcross 2009, McCabe 1999, McCarthy and Thompson 1995).

The Sex and Relationships research started in January 2007, with the remit of finding out more about the experiences and viewpoints of young people with learning difficulties, parents and professionals in this area. It is being carried out using the following methods: a series of drama workshops with young people with learning difficulties age 16-25 over a period of 18 months; a national survey of special schools and colleges; interviews with 20 parents of young people with a learning difficulty; and focus groups with teachers/ governors. The long-term aim of the project is to influence changes in policies and practices around sex and relationships education.

The Sex and Relationships project upholds the social model of disability and is being carried out using an emancipatory methodology, which is a methodology that has been well documented in disability research (eg: M Barnes 1997, Oliver 1992, Zarb 1992). The emancipatory paradigm seeks to challenge issues of power between the researcher and the 'oppressed' group. Within an emancipatory model, researchers have often been conceptualised as providing methodological tools and skills to others involved in a research project but the definition of topic, data collection, data analysis and dissemination is conceived as a joint enterprise. In this way, the control of emancipatory research ends up being in the hands of the 'oppressed' group, in this case, people with learning difficulties, not the researcher. It is pertinent to cite this research project within an emancipatory methodology. Historically, people with learning difficulties have experienced oppression in many areas of their lives, including the area of sexuality and relationships. Undertaking research in a way that is not empowering to people with learning difficulties, can add to their oppression. Therefore, researchers have a responsibility to challenge this, as Oliver (1992: 102) asks:

do researchers wish to join with disabled people and use their expertise and skills in their struggles against oppression or do they wish to continue to use these skills and expertise in ways in which disabled people find oppressive?

The Sex and Relationships project has been careful to address the ethics of the methodology as a key feature. Within the project, people with learning difficulties are empowered within the research process in the following way: they have led the planning and design of the research; a person with a learning difficulty is employed on an equal salary within the research team and is equally involved in the work; a drama group of adults with learning difficulties (The Rainbow Group) has provided expert advice to a drama group of young people; young people with learning difficulties are giving their views and experiences through the vehicle of drama; volunteer adults with learning difficulties are integral to the process of the project; the interviewing phase of the project included interviewing parents with learning difficulties; people with learning difficulties will be fully involved in the dissemination phase and the final report will be written in an accessible way.

Findings

The findings of the research have highlighted a number of areas in which people with learning difficulties experience barriers to sex and relationships. These findings will be covered under the following headings: lifestyle experiences; lack of sex education; and individual barriers.

'Lifestyle experiences'

Within the drama sessions that the young people with learning difficulties (age 16-25) took part in, they were required to make up characters for scenarios. They were very good at thinking of names for the characters, their ages, and their interests. When they talked about two characters meeting each other and fancying each other, they usually came up with the idea that they would meet at school and college. This, in itself is neither ground breaking, nor surprising, but, coupled with the information gathered from the parent interviews, the survey and the focus groups, we have found that one of the barriers facing young people wanting relationships is the lack of places where they can meet people. Within the parent interviews, it was found that quite often, parents kept their young people with learning difficulties close to home, under constant supervision. This way of life was seen as necessary due to the worries around the vulnerability of the young person. One parent said, "My big worry is that she would be taken advantage of." This reflects other research that suggests that some family carers want their children to have the same rights as everyone else but that they are concerned for their safety (Simpson, Lafferty and McConkey 2006). This indicates that the lifestyle experience that people with learning difficulties face in terms of having nowhere to socialize and a lack of their own private space, constitutes a barrier in terms of developing relationships.

The teachers and governors in our focus groups expressed a need for parents and teachers to work together more and for there to be better life skills training for young people with learning difficulties (including training around sex and relationships). Many of the teachers and governors thought that these topics were more important than some aspects of the National Curriculum. In the parent interviews we found that some parents saw their young person as an 'eternal child' and found it surprising when their son or daughter developed physically and emotionally. In this way, parents could also be helped by having more support from professionals on this issue.

However, there are ways in which these barriers can be improved. There have been recent initiatives to address some of these issues, where spaces have been created for people with learning difficulties to meet, away from parents and schools/ colleges. Examples of organisations that have been set up for this purpose are: the Beautiful Octopus Club, a nightclub run by people with learning difficulties, in Leeds and London; Stars in the Sky, a London and Yorkshire based project offering a dating and friendship service; the Stay Up Late campaign, promoted by the punk band Heavy Load that promotes the right of people with learning difficulties to be supported to stay up late; and the Outsiders, a self-help group that provides people with physical and social disabilities, especially those who live in emotional isolation, with help to socialise and form relationships. These new initiatives are addressing the difficulties that people with learning difficulties have in terms of getting to meet other people away from their families. However, in comparison with services for non-disabled people, there is very little provision in this area, so far, for people with learning difficulties. It could be suggested that these services are further adding to the existing array of segregated services, rather than promoting inclusion in mainstream organisations. However, the difference is that these organisations are being driven and promoted by people with learning difficulties themselves and are responding to needs, rather than being set up in a paternalistic, disempowering way.

As discussed in the previous section, within institutional living, opportunities for any kind of sexual experiences were very limited, and there were very few areas where people could have their own privacy (J Collins and Cozens 1999, Shakespeare *et al.* 1996). The issue of privacy has arisen within the Sex and Relationships research as another element of the lifestyle experiences of people with learning difficulties and their parents. The research has found that, in general people with learning difficulties have very little privacy. Examples were given in the parent interviews of CCTV cameras monitoring the movements of people living in supported accommodation and of staff having open access to individual's bedrooms. This, in turn, greatly affects a person's opportunities to be respected for their need to have privacy in a relationship.

Another lifestyle experience identified by the young people in the drama group was around the attitudes of professionals and parents. The young people were good at acting out scenes that showed the differences between 'good' professionals and 'bad' professionals, such as teachers, nurses and doctors. Within the role-play, they intimated that if they told a teacher or doctor that they wanted to have sex or were in a relationship then they were often likely to get negative attitudes in response. They also were aware of some negative responses they might get from parents. In some examples, they suggested that if a person with a learning difficulty wanted a relationship then they should keep it secret so that they would not get into trouble. One young person, for example, when asked about what condoms were for, said that he didn't want to talk about it because he might get 'busted'. There is a case here for training for both parents and professionals so that they have more confidence in addressing the sex and relationships needs of young people with learning difficulties.

The young people in the drama group also acted out some of the difficulties in going to the doctor and about information about sex and

contraception not being written in an accessible format, indicating that family planning services and information about sex and relationships are difficult for people with learning difficulties to access. The lack of services around sex and relationships is another lifestyle experience of people with learning difficulties highlighted by the findings of this project. Research by Shakespeare et al (1996) has indicated that lack of services is also a problem for other disabled people. He talks about one young woman with a physical impairment who wanted to obtain the contraceptive pill and found that most of the family planning clinics she tried to access were not wheelchair-accessible. Shakespeare explains that when she eventually saw a 'friendly' GP, he insisted on offering 'genetic counselling' even though her impairment was not genetic and she had come to prevent a pregnancy. In this way, the attitudes of the 'Eugenics' legacy rears its head again. These lifestyle experiences indicate that people with learning difficulties often experience negative attitudes from professionals. It would be useful for such services to have further training around this issue, to be aware of some of the difficulties people with learning difficulties face and to recognize the rights of people with learning difficulties to have relationships and to be sexual.

Another important aspect of lifestyle experiences comes from the experiences of people with learning difficulties from black and minority ethnic (BME) communities. The Muslim parents who were interviewed in our study, stated that young people in many Muslim families do not have boyfriends or girlfriends because they have arranged marriages. They said that, in general, Muslims do not agree with sex before marriage and that many Muslim families would often not accept gay and lesbian relationships. The following quote from a Muslim woman, that typifies other responses on this issue, shows that culture and religion play a part in her attitudes when she states:

I'm not blinkered to it but I know that culture plays a part in what I think, and the fact that what is my son's ability for understanding...If I didn't have the cultural issue I'd be telling him this and that, but I know the cultural issue holds me back.

The viewpoints from parents from black and minority ethnic communities can be seen as specific lifestyle experiences of some people with learning difficulties and maybe needs further investigation. All services therefore need to be aware of specific values and beliefs that people from other cultures and backgrounds might hold and to be open to having different practices for different people.

The lifestyle experiences of people with learning difficulties identified here, such as, lack of places to meet, attitudes of parents and professionals, lack of services and lack of awareness of cultural needs, can be seen to constitute barriers to relationships and sexuality.

Lack of sex education

Another way in which people with learning difficulties face barriers to relationships and sexuality, is through lack of sex education or clear, accessible information. The Sex and Relationships research was specifically looking at the experience of young people aged 16-25 with learning

difficulties. However, anecdotal evidence from older people with learning difficulties who are employed at CHANGE suggests that sex education was also severely lacking in their own lives. This resonates with research by Shakespeare et al (1996: 24) who quotes one respondent in his research talking about his experience at a special school:

My sex education at school was extremely basic, just confined to the basic sexual act. We were led to believe sex was dirty, frightening and not to be discussed, and only indulged in if you were married and wanted to have children. Until I was in my twenties and thirties I knew almost nothing about contraception and/or safer sex.

Within the findings of the parent interviews in the Sex and Relationships research project, it was found that many parents were positive about the possibility of their sons and daughters having relationships, but that their main areas of concern were around the lack of information and the lack of proactive support from professionals. Out of the twenty parents we interviewed, none had been given any information, as the following two typical quotes suggest:

I've had no information at all; I've had to go and find it myself. I've never been given any information [about sex and relationships] as a parent.

I have a daughter with learning difficulties and the practical thing was managing her own menstruation and the health aspects relating to that. I didn't get any help. It was something I had to investigate myself...

The difficulty in accessing accessible information around sex education still remains a key barrier identified in our study.

Another feature that came out of the drama work with the young people was their frequent reference to television programmes and films as models of relationships and sexuality. This was particularly the case when talking about gay and lesbian relationships, when different examples were suggested from *Emmerdale*, *Hollyoaks* and *Eastenders* (all UK soap operas), among others. Again, it could be argued that non-disabled young people might also get their information and role models from these kinds of sources. However, the parent interviews revealed this to be an issue and, within our study, parents were worried that young people with learning difficulties might be getting *misinformation* from these media sources and that they wouldn't be getting information from other, more reliable sources. Although television seemed to be a key source of information, other media sources, such as magazines and leaflets, didn't seem to be an area where young people with learning difficulties accessed information. In one drama session the facilitator introduced the session by talking about someone putting a letter into a magazine to get a reply from an 'Agony Aunt'. The purpose of this session was to get the young people thinking about possible responses to difficult scenarios around sex and relationships. However, it was found that the young people did not know what an Agony Aunt was. This, in itself, might not be seen as a barrier, but it is an indication that young people with learning

difficulties do not get information from magazines, or written material in the same way as other teenagers might do. The barrier, therefore, is around a lack of accessible information for young people with learning difficulties and lack of printed, visual material that is specifically designed with them in mind.

Some parents in our study made suggestions around the kinds of things that would help in terms of information. One parent said:

It would be nice to have a leaflet with some kind of help line number on it if there was a problem or someone you could phone up to speak to...

Another added:

I do think [it would be good to have] up to date information, up to date plain speaking, good pictures and diagrams, and with a sense of humour to it as well.

One parent suggested that it would be useful to have some kind of pack, with samples and information in it that could be taught at school and that they could use in the home with their son or daughter when the need arose. The parents we interviewed were aware of the importance of providing information to their children in a visual format, rather than just through written words, and several parents emphasized the need to repeat information several times. They pointed out that some young people with learning difficulties forget information that is taught to them or may not understand it the first time.

Among the parents who were interviewed, most of them felt that they, as parents, were often left with the responsibility of teaching their children about sex education. One parent said that, at the end of the day:

no-one is going to give her [my daughter] that information except for me, I would think. There's no other source for her. She wouldn't dream of going looking for it. My daughter has only just started making her own hair appointments so she isn't going to go to a family planning clinic.

Many parents felt that professionals should play a bigger role in giving their sons/ daughters information and that professionals should give parents more support. When asked, 'Who do you think should provide information to your son about sex and relationships?' many of the parents said that it shouldn't be down to one person and they expressed the need for partnership working. Suggestions of the kinds of professionals who could be involved, included community nurses, social workers, support workers, youth workers, occupational therapist, teachers and doctors.

In terms of giving young people with learning difficulties effective support and information in the area of sex and relationships, a number of parents felt that it would also be useful to meet up with other parents. The parents felt that this would give them the confidence to tackle some of the issues and to find out from other parents how they had gone about addressing issues around sex education with their own sons and daughters. One parent commented:

Unless parents have mixed with other parents that are kind of confident and feel able to express and have been through that, which I don't think happens enough still, because quite a lot of parents do it in isolation, then they don't feel confident...

Another parent pointed out that, in general, parents of young people with learning difficulties who go to mainstream schools tend not to meet each other in the same way that parents of young people in special schools might do:

If they go to a special school they tend to have a parents group, the parents go along even if it's just to have a cup of coffee once a month and you talk. When the children are in mainstream there is no opportunity to meet up...I think it's a very important part of having a son or daughter with learning difficulties or additional needs, talking to other parents.

However, other parents stated that parents of young people in special schools also have difficulties meeting up because of the large catchment area of the students who attend the school. In this way, therefore, there is perhaps a need to provide *all* parents of young people with learning difficulties the opportunity to meet together for support and information on this issue.

Most teachers/ governors in the focus groups said that they would like better training to teach sex education. This would also give them more confidence on the issue. They also stated that it was important for teachers and parents to work together on the issue and that parents should play a big role.

Individual barriers for people with learning difficulties

A social model of disability highlights the way in which people with disabilities experience difficulties arising from the environment in which they live in and from other people's attitudes. The historical legacy, lifestyle experiences and lack of sex education for people with learning difficulties are such examples since they arise from external difficulties in the environment and in other people's attitudes. However, the Sex and Relationships research has highlighted some individual barriers that people with learning difficulties experience that could be defined as a consequence of their impairment, rather than the environment, that is, a medical model point of view. Within the focus groups, for example, the teachers/ governors highlighted the difficulties that some people with learning difficulties have in communication. The teachers/ governors in our study felt that difficulties in communication meant that young people with learning difficulties may not be able to verbalise questions, anxieties or worries. Therefore there is also a case to be put forward for giving students very clear information so that they have fewer worries and have more understanding about what is happening to their bodies and emotions as they develop.

The teachers/governors suggested that problems in communication also went hand in hand with problems in levels of understanding. They stated that much of the sex education resources they had for use in special schools were not at a level that many of their pupils could understand, and there was particularly very little information for people with severe or profound difficulties.

Within the Sex and Relationships research, it was pointed out that young people with learning difficulties in mainstream schools might get sex education but it was not taught at a level that they could understand and there was often not any individual support or segregated classes to explain the information more thoroughly or to go through the information at a pace to suit their level of cognitive understanding. However, within the focus groups with teachers and governors, it was found that, even though young people with learning difficulties in mainstream schools did not get the support to understand the sex education they receive, the young people in special schools were perhaps getting even less direct sex education teaching. The teachers and governors suggested that most sex education in many special schools was done on a one-to-one basis as and when required, or if a specific 'problem' arose.

Although young people with learning difficulties in mainstream school might not understand the sex education they have received, Shakespeare et al (1996) found that there were many positive aspects of disabled young people being in a mainstream school, including the expectation that they will become a sexually active adult. Being a young person with a learning difficulty in a mainstream school, therefore could be seen as a double-edged sword: on the one hand, sex education might not be taught at a level the individual can fully understand, but on the other hand there may be more expectation that they would be able to be involved in having relationships, like any other young person. Difficulties with communication and with understanding therefore can be seen as individual barriers that are attributed to a person's learning difficulty, rather than to external forces.

In many cases it may not be possible to improve an individual's level of communication and understanding, but the findings from the research highlight the need to present information at a level that is appropriate to the young person. It also suggests that sex education might be best delivered by a person (or jointly) who has built up good relationships with the young person and understands the ways in which they communicate.

Within the focus groups with teachers and governors, worries arose over lack of suitable resources to use. They said that DVDs were good for some pupils, but they had some pupils who could not concentrate on watching a DVD and needed something more tactile and interactive, such as anatomically correct models. One example of an innovative project using more visual/tactile methods of teaching sex education to people with learning difficulties is the Josephine project, in Newcastle, which uses a life-size female cloth model with an abdomen that can be opened up to reveal internal, reproductive organs. The Josephine project has delivered one drama session with the young people in the Sex and Relationships project and it was very well received, with the young people saying that they thought the model was 'awesome'.

Discussion: Addressing Social Exclusion

This chapter has identified the following as barriers to sex and relationships for people with learning difficulties: historical legacy, lifestyle experiences, lack of sex education, and individual barriers. Some of these barriers can be addressed through changes in policies and practices. Others, such as attitudes that arise from a historical legacy, and some individual barriers, are

harder to change. The challenge seems to be based on the need to protect people who are labeled as vulnerable, balanced with the rights of all human beings to have relationships and family lives.

It must be stressed that, for any group of people who have had an historical legacy of oppression, an individual's personal experience becomes collectively, an indication of wider political issues. Within the area of sex and relationships, it could be suggested that the experiences of individual people with learning difficulties all add to the wider political process of social exclusion. Barnes (1991) and Borsay (2005) show that people with disabilities have had a history of exclusion from work, particularly since the industrial revolution, which has been attributed to the change in the nature and organisation of work. More recent research from Barnes and Mercer (2005) find the barriers to work for disabled people continue to be linked to the social organisation of work and serves to exclude those with an impairment. They argue that this exclusion is not confined to employment but is part of a wider social exclusion created by structural barriers and inadequate access to education, information, and the physical environment. The outcomes of the Sex and Relationships project reiterates this by suggesting that social exclusion exists in other areas of the lives of disabled people, outside of employment. In this way we would argue that the area of relationships and sexuality needs to be added to the social exclusion agenda.

The term "social exclusion" has become increasingly important in discussions of poverty and inequality since the 1990s (Levitas 1998, Parkinson 1998, Room 1995, Silver 1994, Walker and Walker 1997) but it has recently been expanded to include other factors, such as rights and discrimination:

it [social exclusion] draws attention to a combination of economic hardship and institutional discrimination, both of which help to create unfavourable life chances and chronic exclusion from normal citizenship (Mingione 1997: 10).

Within the Sex and Relationships research we have highlighted the ways in which people with learning difficulties have experienced institutional discrimination and thus, unfavourable life chances, in the area of sex and relationships.

Gordon et al (2000), researched poverty and social exclusion in Britain, and distinguished between four dimensions of exclusion: impoverishment, or exclusion from adequate income or resources; labour market exclusion; service exclusion; and exclusion from social relations. The Sex and Relationships study has highlighted that people with learning difficulties experience service exclusion in terms of lack of access to family planning clinics and professional advice services. Gordon expands his category of 'exclusion from social relations' to include the following: exclusion through non-participation in common social activities; exclusion through isolation; exclusion through lack of support; exclusion through disengagement; and exclusion through confinement. Gordon (2000: 65) goes on to explain confinement:

In addition to factors such as affordability, childcare responsibilities, being too old, disabled or sick, or lack of time due to paid work...other factors are involved which leave people substantially confined to their home and, in less extreme cases, reduce their level of activity.

The Sex and Relationships project identified that people with learning difficulties are often 'confined', due to non-participation in social activities (ie "lack of places to meet"), isolation, lack of support, and in the extent of supervision they have from adults. This adds to the argument that people with learning difficulties are socially excluded in the area of sex and relationships.

Although some changes in services, laws and rights in the UK have been made, subtle forms of prejudice can remain. This has been indicated by the negative attitudes around sex and relationships (probably as a result of the historical legacy) faced by people with learning difficulties in our research. Barnes (1991: 197) explains how disablist attitudes are developed:

Just as racist or sexist attitudes, whether explicit or implicit, are acquired through the 'normal' learning process, so there is evidence that 'disablism' is learned in this way too.

We have argued that a historical legacy of Eugenic attitudes can contribute to disablist practices and policies around sex and relationships, particularly for people with learning difficulties.

In the UK, the Special Educational Needs and Disability Act (SENDA) 2001 states that it is unlawful for Schools, colleges, universities and providers of adult education to discriminate against disabled people. These legal duties make it unlawful for providers of education to treat disabled people less favourably and requires them to make 'reasonable adjustments'. Educational institutions have a duty to make reasonable adjustments to all aspects of school/college life, including policies, practices and procedures, so that young disabled people are not placed at substantial disadvantage. This suggests that legislation supports the inclusion of people with learning difficulties in all aspects of education. However, the Sex and Relationships study has found that young people with learning difficulties may be placed at a 'substantial disadvantage' in the area of sex and relationships, thus adding to disablist attitudes and practices. Added to this, young disabled people may "learn to have low expectations about their own future contribution to society, as a result of the way in which they are treated" (Gray, 2002, cited in L Wilson 2004: 163). The findings of the Sex and Relationships research suggest that young people with learning difficulties may come to have lower expectations about their own future relationships because they are not getting the information, support and encouragement on this issue.

Stewart argues that exclusion is "both the state of being shut out and the processes by which the shutting out occurs" (Stewart 1999: 11). In this way, Stewart is recognizing the need to address how the structural processes in society create and feed the experience of exclusion. This chapter has explored the nature of the ways in which people with learning difficulties are 'shut out' of experiences around sex and relationships, and the processes by which shutting out has occurred, including, the influence of historical practices and attitudes. Within the 1980s, the concept of normalisation became

prominent, its principle being to make available to people with learning difficulties:

patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society' (Nirje 1985: 67).

The concept of normalisation was a step forward in terms of improving the attitudes toward, and treatment of, people with learning difficulties. However, Shakespeare et al (1996: 25) states:

Whereas in other areas of life the trend is towards 'normalisation', in other words, fitting people with learning difficulties into the roles and values of the rest of society (Wolfensburger, 1972), this does not seem to prevail in the area of sexuality.

This suggests that present models of social exclusion, with their focus on employment, may not be adequate to explain the whole experiences and the perception of people with learning difficulties in present day society.

Barnes (1997) is positive in relation to the role of previously oppressed groups when she states:

groups of people who have occupied subordinate and powerless positions are seeking to have their voices heard in decision making forums. People excluded from social, economic and political life are seeking to participate in those spheres as well as to participate in decision-making about those services of which they stand in need. They are asserting that people constructed as passive recipients of care can be actors playing a part not only in the production of welfare, but also on the wider social stage.

People with learning difficulties therefore need to be empowered to take action and be political, to campaign for better services and attitudes, and to be involved in the structures and systems of society. In terms of the group of people collectively known as 'disabled people', people with learning difficulties can often be a 'minority'. Shakespeare et al (1996: 190) suggests that the disability movement needs to change to be more inclusive, when he says, 'the disability movement needs to ensure that 'minorities' within its ranks are empowered to participate and that their issues are presented as issues for the 'majority'".

Building capacity among groups that have been excluded is often the way in which social change takes place (Craig and Mayo 1995, Dominelli 1990, Mayo 1994). Barnes (1997: 162) states:

user and carer groups are concerned not so much with social change in terms of redistribution of resources...as with opening up decision-making processes and thus achieving change in the way in which issues are being thought about and discussed.

Despite the introduction of the Disability Discrimination Act in 1995, people with learning difficulties continue to be excluded within society. There are very few images of people with disabilities in society, which, in turn, can affect the aspirations of people with disabilities. Shakespeare et al (1996: 18) states:

Disabled children, like their non- disabled peers, need to know that the world has endless opportunities open to them and their destiny is shaped by a combination of personal preference and choice, not by imposed restrictions by frightened care-givers.

The following needs to happen, therefore so that people with learning difficulties experience social *inclusion*: the empowerment of people with learning difficulties to take action, be political and campaign for better services/attitudes; the disability movement needs to be more inclusive of people with learning difficulties; and people with learning difficulties need to be more visible and valued members of society with positive role models and images.

People with learning difficulties are excluded in many areas of society; this has arisen from the 'historical legacy' of being seen as different and by not being recognized as having value as human beings. From our research, we have found that this is particularly true within the area of sex and relationships. We have found that through the personal experiences of young people, parents, teachers and governors, wider issues that constitute social exclusion have been discovered. Within the Sex and Relationships research, the importance of an emancipatory methodology cannot be stressed highly enough. The 'voices' of young disabled people and their parents/carers are rarely heard in research, but in order to understand the nature of their experiences of social exclusion, the Sex and Relationships research is documenting these aspects of their lives. By giving people with learning difficulties power in the research process they are, at last, making their voices heard. We have found that they have important things to say.

CHAPTER 6

Disability, Masculinity and Sexuality in Post-Soviet Ukraine

Sarah Phillips

Accessible Summary

This chapter talks about sex and relationships for men in Ukraine who have spinal injuries. It shows how men who become disabled might change their ideas about how to be a man. Because of their disability, they can't always do things society expects men to do, like be the head of a family or have sex in the "regular" way. But the men we talked to say they can still be "manly" in their own way. We did some research on this and here is what we found out:

- Society does not expect men with spinal injuries to have a sex life and may not see them as "real men."
- Men with spinal injuries don't all agree on what "real men" are like. Sometimes their ideas depend on their age, ethnicity, past life experiences, and so on.
- Physical strength and trying to stay mobile through sports seems very important for men with spinal injuries.
- Many men with spinal injuries find it hard to have a family. Disabled people in Ukraine are not allowed to adopt children.
- Sometimes women don't think of disabled men as whole men, so it is hard for disabled men to have strong and longtime relationships.
- Men with spinal injuries seem more likely to have sex that is kind of adventurous. They are willing to experiment. When men become disabled sometimes they look for new ways to express themselves as men. They might take up a new hobby or a sport, for example. In Ukraine and lots of other places there are strict ideas about what women and men should be like. When someone becomes disabled, it can be hard for them to fit these ideas. The men we studied in Ukraine had spinal injuries that made it hard for them to get around, to be independent, and to have sex and relationships. So other people wondered if they were still "real men." But the disabled men found ways to still be manly in their own way, by doing sports and physical training and experimenting with different kinds of sex. We can all learn a lot from these men: there are many different ways to be a man or to be a woman.

Introduction: Ethnographic Explorations of Spinal Cord Injury, Masculinity and Sexuality

9 May 2005. Kyiv, Ukraine. Today was Victory Day, marking the sixtieth anniversary of the victory of the Soviet Union over Nazi Germany in the Second World War. My friend Dmitrii (a pseudonym), a wheelchair user, invited me to watch the Victory Day parade with him and the members of the club for youth with disabilities that he has directed for the last several years. I saw Dmitrii already waiting for me when I emerged from the subway station into a light drizzling rain, and I walked to meet him at our designated meeting place in front of the

Central Post Office. We exchanged the customary and friendly kiss on the cheek upon meeting, and then hid under my umbrella as we chatted and waited for the others. An elderly man using crutches (possibly a WWII veteran) walked up to us, looked at Dmitrii in his wheelchair, then at me, and said, "You are a real woman." He proceeded to wish us health and happiness, and told Dmitrii to value me and keep me close. We both struggled to suppress our giggles—the man clearly assumed Dmitrii and I to be a "family pair," and we were embarrassed (I am married, and Dmitrii has a steady girlfriend).

Although we both took it in stride and started talking about something else after the man walked away, the atmosphere suddenly had changed. I think Dmitrii interpreted the man's words thus: "You are really lucky that you, an 'invalid,' have a woman to take care of you." I also felt I was being praised for my 'self-sacrifice' in caring for and loving an "invalid," as people with disabilities are commonly called in Ukraine and other post-Soviet countries. Suddenly Dmitrii, a 38-year old athlete and independently-living director of a non-governmental organization (NGO) was thrust into the role of a marginal, dependent "invalid." Dmitrii and I never revisited the incident but it prompted me to take notice of how people's experiences of disability intersect with formations of gender, masculinity, femininity, and sexuality, questions that have been little explored in the post-Soviet context (edited field notes).

In this article I seek to understand how having a disability affects men's ability to enact gender in contemporary Ukraine, a postsocialist society in flux. Although Ukrainian women have been the focus of recent studies that examine changing gender regimes after socialism (Phillips 2008), little attention has been paid in the scholarly literature to men's changing roles and negotiations of masculinity. Considerations of the gendering of disability are even sparser, although some research on disability and gender has been conducted in Russia (Iarskaia-Smirnova 2002a, b, Indolev 2001: 110-146). In this initial examination of the intersections of disability, masculinity, and sexuality in Ukraine, I begin by asking general questions similar to those posed by Thomas Gerschick in his influential article, "*Toward a Theory of Disability and Gender: How does disability affect the gendering process? How does it affect the experience of gender?*" (2000: 1263). Also following Gerschick (2000: 1267), I consider, how might the stigmatization and marginalization that women and men with disabilities face contribute to the creation of alternative gender identities?

I approach these broad theoretical questions in a manner that is ethnographically grounded. Ethnographic perspectives, which locate theoretical analyses in the day-to-day lives of persons in ways that are very experience-near, can contribute valuable insights to the emerging literature on disability, sexuality, and masculinity. As Russell Shuttleworth has noted, there is a real need to move from an abstract level of analysis to richer perspectives that can adequately explore how "the performance of gender occurs in sociocultural contexts" and emerges from "embodied practices [and] interpersonal negotiations" (2004b: 169). For this, we need more research

that involves long-term participant observation, multiple personal interviews over time, and the cultivation of relationships between researcher and informants—in other words, good old-fashioned anthropological/ethnographic fieldwork.

I have been researching disability issues in Ukraine since 2002. This work has included participant observation with more than 20 advocacy NGOs and 90 extensive interviews with activists, lawyers, scholars, and government officials. Here I explore the life history narratives of two men with disabilities who live in Kyiv, Ukraine's capital city of 2.7 million people. These men's stories confirm Shuttleworth's (2004) thesis that the experience of disability may enable men to expand the masculine repertoire and shed some of the constraints of hegemonic masculinity. Research on disability, masculinity, and sexuality across cultures increasingly shows that the experience of being disabled might present men with opportunities to subvert traditional and limiting gender expectations and to change their sense of self as men, workers, and sexual subjects in unexpected and empowering way (Iarskaia-Smirnova 2001, 2002a, b, Shuttleworth 2004b, B Smith and Sparkes 2004, Sparkes and Smith 1999, 2002). This research also reveals, however, that these processes are uneven, and may involve a simultaneous reliance on and rejection of hegemonic masculinities in a given context.

The ethnographic material from Ukraine detailed here suggests that the expansion of masculine repertoires is also possible in a post-Soviet society where gender norms and notions about disability still are informed at least partially by the strict gender role stereotypes, patriarchal attitudes, strict body cultures (Brownell 1995), and institutional structures of power of the Soviet regime. By aligning themselves with the standards of hegemonic masculinity in certain situations, or in particular aspects of their lives, but undermining such ideals in others, some men with disabilities in postsocialist Ukraine have been able to redefine, and reimagine themselves and what it means to be a "real man" in this rapidly changing society. These negotiations are in many ways tied up with the political and economic transformations that have swept the country during the last decade and a half, making post-Soviet states such as Ukraine especially interesting sites for investigating how disability experience intersects with larger political and social forces in identity formation.

My research has involved primarily persons in wheelchairs and others with mobility disabilities. The "*spinal'nik*," or "spinally-injured" community is a particularly apt site for tracking intersections of disability and masculinity, since more men than women in Ukraine become disabled as the result of spinal injuries, and men appear to dominate in leadership positions in NGOs that center on issues of mobility disability. Most nationally-recognized *spinal'niky* are men (with the exception of Svitlana Trofinova, the well-known and much loved paralympic athlete), and in the popular imagination, spinal injury, wheelchair use, and the general category of *spinal'niky* are all associated more with men than with women.

These dynamics confirm Gerschick's (2000: 1265) assertion that:

for men with physical disabilities, masculine gender privilege collides with the stigmatized status of having a disability, thereby causing status

inconsistency, as having a disability erodes much, but not all, masculine privilege.

The life history interviews I conducted revealed that as their masculine privilege is eroded as a result of the stigma of disability, men in Ukraine seek not so much to hang on to this privilege as to forge new paths to being men in the face of disempowering stereotypes about men with disabilities. Depending on men's life circumstances, at times this may entail striving to enact hyper-masculine qualities in some area(s) of life, but just as often it involves a rejection of hegemonic visions of masculinity and includes a reimagining of one's own possibilities to "be a man."

"How Are Those Disabled People?" Men's Personal Narratives of Disability, Masculinity, and Sexuality

The case studies that follow are based on life history interviews and casual conversations with two well-known members of the *spinal'nik* community in Kyiv: Dmitrii (from the opening vignette) and Anton (also a pseudonym). I have known Dmitrii since 2002, and I met Anton for the first time during 2005. I have conducted approximately 20 hours of taped interviews with Dmitrii, and have spent many more hours with him in one-on-one conversations and in group talk and activities. During 2005 I conducted a four-hour-long taped life history interview with Anton, interviewed him over the telephone for several more hours, and also enjoyed lengthy informal face-to-face discussions. Follow up research was conducted with both men during fall 2006.

The focus of my interviews and conversations with these men was not specifically their negotiations of masculinity and disability, but these questions did sometimes emerge in the course of our conversations. Dmitrii and Anton knew that I was interested in a broad range of issues relating to disability—including gender, masculinity, and sexuality—but I did not press the subject unless they initiated it themselves or seemed open to such a discussion. The cultural taboos surrounding sex and discussions of it in the former Soviet Union affirm the importance of long-term ethnographic research and the establishment of trust in researcher-informant relationships in order to adequately investigate certain topics. Among my informants Anton was exceptional in the openness with which he discussed issues of sexuality in both abstract and personal terms. By contrast, I had known Dmitrii for several years before we were able to have in-depth discussions about sexuality.

It is important to note that both Anton and Dmitrii became disabled in their twenties, after they had already become adults, begun careers, and established gender identities. As well, they received traumatic spinal cord injuries right around the time of the fall of the Soviet Union amidst immense political, societal, and economic upheavals. Their stories therefore are illustrative of the intersection of a range of factors on identity formation, including disability, masculinity, and sexuality, but also ethnicity, age, and political, social, and economic change. Although I certainly would not claim these two cases studies as representative of men's experiences of disability in Ukraine as a whole, I do believe that Dmitrii's and Anton's stories get at many important aspects of how men currently are negotiating disability, masculinity, and sexuality in their lives. In analyzing their narratives I am also drawing on my familiarity with broader dynamics of gender negotiations and disability

processes in Ukraine, as well as my knowledge of the narrated experiences of other men and women with disabilities.

Dmitrii

In 1989, Dmitrii was in his early twenties when he was injured in an industrial accident. He received a blow to the back resulting in an incomplete compression fracture in the lumbar region (L1-L5). When describing how becoming an “invalid” affected his sense of self, Dmitrii once said:

As a teenager, when I was still healthy, I was afraid of ‘invalids.’ I didn’t know who they were, or what had happened to them. Myself, I felt like Duncan McCloud [the Highlander]—immortal.

For a year after his injury Dmitrii underwent intensive rehabilitation therapy with the assistance of a network of friends who lived with Dmitrii and his aging mother on a rotating basis.

Before his injury Dmitrii was employed as a tank driver and sniper in the Soviet army, and later as a metalworker and a welder. Since his injury he has not held official and steady employment, despite his self-description and self-perception as a “blue-collar worker.” Other than payments for some temporary and unofficial jobs, his primary source of income has been a disability pension. The base yearly disability pension for individuals with disabilities who are considered unable to work is 3,984 Ukrainian hryvnias (UAH), or just \$792. There is a strong popular perception that “invalids” are and should be poor and destitute, and people with disabilities are thus denied the possibility to establish economic independence, one of the major prerequisites for postsocialist citizenship and the postsocialist assertion of masculinity. A few years ago Dmitrii became the director of an NGO, a position that sometimes substitutes for paid employment and has opened up a range of quasi-business opportunities for him.

As is common in Ukraine, where, as one friend put it, “If doctors say you won’t walk again they think they are giving you a death sentence,” for years Dmitrii thought of his wheelchair use as a “temporary setback.” In addition to rigorous physical training, Dmitrii also endured more than 20 surgeries, which finally resulted in the partial amputation of one leg. This is just one example of the medicalization of disability in postsocialist states like Ukraine (and many other places); in the case of Dmitrii we see a certain type of medicalized masculinity (Rosenfeld and Faircloth 2006) in which mobility (“walking again”) is made central to manhood and “overcoming” traumatic injury and disability. Other informants told lengthy stories about different courses of rehabilitation they had undergone in Kyiv and other locales, confirming Russian sociologist Elena Iarskaia-Smirnova’s (2002a) observation that “rehabilitation experiences” and “mobilizing events” are central themes in disabled men’s life history narratives in the former USSR.

Although there is a major push amongst disability rights groups in Ukraine for universal design and accessibility, for many persons—men especially—with disability the day-to-day locus of mobility (and rehabilitation) remains the individual body, a situation that subverts worldwide disability rights perspectives. Since public transportation is inaccessible to wheelchair users, Dmitrii travels almost everywhere he needs to go in his push

wheelchair, using the busy city streets. On an average day he covers 15-20 miles, which can take as long as 2.5 hours. Like most buildings in Ukraine, the apartment house where Dmitrii lives is not wheelchair accessible, so to reach his apartment he must navigate a flight of stairs in his wheelchair. In the absence of accessible buildings and spaces, the spinally-injured are encouraged to “work on themselves” through programs of active rehabilitation (initially introduced by Swedish disability rights activists), and to focus on their own physicality and personal mobility. In some ways such programs privilege men, since negotiating barriers such as curbs and steps requires a great deal of upper body strength that women may not possess. Inevitably, though, wheelchair-users like Dmitrii sometimes must ask for assistance from passersby, a situation that seems to deal a psychological blow to men in particular.

Dmitrii’s stories about his attempts to use public transport and elicit help from bystanders often included reflections on masculinity as he juxtaposed himself with other Ukrainian men. Dmitrii complained that men always seem reticent to help lift him and his wheelchair into a bus or tram, or up steep stairs, while women and “little homeless kids” are always ready to assist. During one interview he said:

Once a group of nuns carried me into a church. There weren’t any men around, only meatheads (Rus. *mudaki*), excuse me for the expression... Sometimes I come up to the tram or the bus and ask a guy (Rus. *muzhik*), “Can you help?” Suddenly he develops 48 illnesses on the spot—“Oh, my finger hurts, my back is out...” Most often it’s women who help. As they lift me into the tram I look around and say loudly, “Well, looks like there are no men left. They must have all fallen in the Kulikov battle [between Russians and Tatars in 1380]; we’re left with only meatheads”.

Here Dmitrii contrasts his own robust physical condition (he has likely traveled miles in his wheelchair to reach the bus) with that of the (non)-men who refuse to assist him, and he criticizes these men for their lack of strength, goodwill, and chivalry as women struggle to lift him into the bus.

In this regard Dmitrii’s vision of masculinity and being a “real man” maps onto the image of the *voniuch, moguch, i volosat* (Rus.), someone who is “stinking, strong, and hairy.” This commonly-used trope neatly indexes the ideal or hegemonic masculinity in Ukraine and points to some of the more salient cultural symbols of manhood—physical strength (and being able to protect others, especially one’s own family), possessing a certain rawness and burliness of physique (as represented in one’s “hairiness”), but lacking a fixation on one’s appearance and not being too obsessed with one’s personal hygiene (also denoted by “hairiness” and the presence of body odor, the latter simultaneously evidencing one’s hard work). The trope of *voniuch, moguch, i volosat* points to the centrality of the body and a particular body culture to enacting gender in post-Soviet Ukraine, and it underlines especially the importance of the body as a marker of manhood.

In Dmitrii’s reflections on “real men,” he overtly underscores the importance of physicality and physical strength to “manliness.” Indeed, in Russia, Iarskaia-Smirnova (2002a: 124) notes that physicality seems to be

more important in identity formation for disabled men than for other men. I also found that in Ukraine, maintaining optimum mobility and a developed physique is an important part of the sense of self and sense of manhood for many men with mobility disabilities. Some of the first state-sanctioned disability awareness events in the former USSR revolved around sport and extreme displays of physical fitness, such as the “super-marathons” undertaken by several wheelchair users in 1991 and 1992. Three men—Russians Iurii Shapovalov and Evgenii Kolychkov, and Ukrainian Oleksandr Sukhan—undertook the 1992 super-marathon from Vladivostok to St. Petersburg, Russia, covering a distance of 11,000 kilometers in their wheelchairs. Sports is a major focus of the disability rights movement in Ukraine today, and the paralympic movement has made dramatic progress in recent years under the direction of Valery Sushkevych.

Sports play a crucial role in Dmitrii’s life, even though he was not very interested in sports before his injury. During the last 15 years Dmitrii has been active in a vast array of wheelchair sports, from track and field to billiards and basketball. During my initial visit to Dmitrii’s apartment, he immediately began to talk about sports and showed me all the medals he had won in various competitions.

The conventional view is that sport serves as an avenue for men with disabilities to recover “lost” masculinity by tackling physical challenges and developing the physique. But writing of Russia, Iarskaia-Smirnova reflects on the more complex role that sport occupies in the lives of many persons with disabilities, especially men:

Public activity, and the feeling of belonging to a team or a collective, allows an individual to reevaluate personal identity: to be less disabled and more courageous. However, courage in disability in this context does not exactly align with the dominant canon of masculinity. Here, rather, we find articulate not the domination of invulnerable strength, but *difference* [as one disabled athlete said]: “*I am an inconvenient* [Rus. *neudobnyi*] *person...*” Here, the personal becomes political (Iarskaia-Smirnova 2002a: 121).

Indeed, in Ukrainian disability sport there is often an element of awareness-raising and political protest, as represented by the yearly “Treat me as equal” demonstration in Kyiv, where wheelchair users educate the general public about wheelchair sports and issues of accessibility. On the other hand, as personal interviews with men such as Dmitrii have shown, it is true that sports may hold intensely personal meanings for individuals, and sport has the capacity to help men gain self-confidence after traumatic injury, come to terms with their new “disabled” identities, and explore new visions of masculinity for their own lives as disabled men.

Until very recently, the topic of disability and sexuality in Ukraine and other post-Soviet countries was a closed one. As one of my friends (an NGO director who is also the mother of a spinally-injured young man) said, “People can’t seem to utter the word ‘invalid’ and ‘sex’ in the same sentence.” Iarskaia-Smirnova (2002b) concludes that the sexuality of disabled persons receives two primary and contradictory treatments in scholarly and popular accounts: it

is either medicalized and treated as inherently and inevitably problematic, or the sexuality of disabled persons is exoticized (i.e. disabled men are hypersexualized). Heterosexuality is always presumed, and there is no mention of homosexuality or any other “alternate” sexualities.

Cultural myths about sex and disability abound, and in one article sexologist Iurii Prokopenko (2001) succinctly unravels seven “misconceptions about the sexual life of ‘invalids.’” (The article itself is very problematic in the language used to describe people with disabilities—Prokopenko refers to “defectives” (Rus. *nepolnotsennye*) and “idiots” (Rus. *debily*.) These misconceptions are the following: 1) They are asexual; 2) they are helpless and therefore in need of protection; 3) they should marry only other “invalids”; 4) parents of “child-invalids” do not want to educate their children in matters of sexuality; 5) an orgasm is the only path to sexual satisfaction; 6) sexual problems they experience are necessarily a result of their disability; 7) a non-disabled person engages in sexual relations with an “invalid” only if he has no choice.

At the end of the first life history interview I conducted with Dmitrii in 2002, he told me of an encounter he had with a young woman, Tanya, whose reaction to him he described as “typical” in its denial of “manhood” to men with disabilities in Ukraine. During a weekend at a friend’s dacha in the countryside, Dmitrii spent the night with Tanya, who appeared sullen and very quiet the next morning. That afternoon the group of about ten young people was sitting around the table, eating and talking, when Dmitrii finally asked her, “Tanya, what’s wrong with you? Why are you so quiet?” Dmitrii told me what happened next:

She said, “You know, Dmitrii, I didn’t know you were a man.” It grew silent as the grave around the table, and I remember one poor guy just standing there with his shish kebab, and his mouth hanging open.

During another interview Dmitrii jokingly reflected on the pervasive ignorance that surrounds disability and sexuality. To illustrate, he told of a recent encounter he had with a (woman) pharmacist in Kyiv, when he wanted to buy a condom catheter. She had no idea what Dmitrii was talking about, and when he described the item as “a condom, for invalids, with a little ‘pip’ on the end,” she asked what the little “pip” was for. Dmitrii could not resist joking with her: “It gives us a better chance of impregnating a woman.” “Really?” the woman asked wide-eyed, “How?” Dmitrii continued, “It directs all the sperm into one powerful jet.” Dmitrii reflected back on the incident, “She’s a pharmacist; it’s her job to know these things. If that’s her level of knowledge, what can we expect from the general public?”

My research has shown that in Ukraine there is a pronounced lack of local discourse—or even a local lexicon—for discussing what some informants called “disabled sex.” This does not indicate a lack of interest, however. On the contrary, one NGO leader who has translated some English-language materials on disability and sexuality into Russian and Ukrainian for distribution among the *spinal’nik* community in Ukraine said that these booklets are her most popular item. Similarly, one friend noticed that, at a sanatorium for the mobility disabled where he received treatments a few years ago, the chapter on love and sex from all of the sanatorium’s copies of the

book *Zhit' v kolyaske* (To live in a wheelchair) by Russian disability rights activist and journalist Lev Indolev (2001) had gone missing—people simply ripped out the treasured chapter and took it home with them for future reference.

For Dmitrii, wheelchair sport dance has been a way to deal with the feelings of inadequacy “as a man” that plagued him after he became disabled and began using a wheelchair. Although Dmitrii often made joking sexual references in casual talk, it was not until I had known him for three years that he began to tell me about what he called his “sexual fears” after his injury. Once at a café after I told Dmitrii about my struggles to overcome shyness around new acquaintances, he also began to discuss his personal “complexes:

I'm a normal guy, I love women, I like to have fun, but I find it almost impossible to take the next step with a woman. To be honest, I began dancing in order to overcome this terror (Rus. *strakh*) in front of women.

Dmitrii said that dancing has given him “some kind of emotion, some kind of passion that goes beyond the mechanics of the dance itself.” He described dancing as a means to interact with a range of people, including the non-disabled, and especially women, and as a way to be physical and “put myself on stage” in a way that is affirming and, at times, erotic. He hopes that, having gained confidence in himself as a performer, and by cultivating new bodily experiences brought to him through the physicality and emotion of dance, he will feel more comfortable initiating intimacy with women. Thus although Dmitrii does at times draw on and seek to embody hegemonic notions of masculinity, with emphasis on strength, chivalry, and other “manly” qualities, through dance he also seeks to broaden the masculine repertoire to include emotion, passion, and a kind of alternate life rhythm that he sees himself as uniquely situated to enjoy as a disabled man.

One unintended effect of this, however, is that Dmitrii's image has been appropriated by others; he cuts a striking figure when dancing, and exudes confidence, playfulness, and feeling. As has been described for other places, in Ukraine individuals with disabilities are sometimes thrust into the role of moral hero, inspiring models of moral fortitude. Indeed, men with disabilities are lauded in the popular media when they are perceived to exhibit traits such as determination, courage, and strength, those qualities seen as appropriate to an “ideal man” who has fallen into harsh conditions (Iarskaia-Smirnova 2002a: 123). Dmitrii's story has been recounted in many venues, including newspapers and inspirational documentary videos. However, at times he becomes a depersonalized hero, since his photograph is frequently found in the pages of newspapers and journals without any explanation or story about Dmitrii. In such appropriations Dmitrii is sometimes assigned a sort of hypersexual identity—one acquaintance insisted that “only Dmitrii would do” as the “star” in a how-to video on “sex for the disabled” she was planning, a project Dmitrii rejected and jokingly dismissed as “porn for invalids.” He mused, “I already have a sort of wild reputation—what would people say about me if I bared my butt in that video?”

One of Dmitrii's major regrets is that he will likely not become a father; as he said, "The doctors say it isn't going to happen." Dmitrii was married for a short time to a woman (also a wheelchair user) who left him for a man with whom she subsequently had a child. The failed marriage was not so much a blow to Dmitrii as the fact that he could not have children with his wife. Adoption is not an option, since laws in Ukraine prohibit persons with disabilities from adopting children. Similar barriers to adoption exist in Russia, and Lev Indolev (2001: 130) posits the state's reasoning thus: "The state...assumes that [persons with disabilities] cannot raise a child or—even worse, supposes that they will begin to exploit the child." People like Dmitrii are thus officially denied parenthood, a key component of masculinity (and femininity) in the culture. Dmitrii acts as a sort of surrogate father for the youth in the NGO he directs, and in the past he was also a popular "first contact person," an individual designated to visit persons in hospital with new spinal cord injuries to talk positively about life after traumatic injury.

Dmitrii is currently not married but is in a long-term relationship with a woman with a history of bisexuality. A few other spinally-injured men I interviewed also noted that their sexual partners and girlfriends tend to be women who are open to bisexual relationships, "threesomes," "creative positions" and innovative ways of receiving and giving sexual pleasure, all of which go against the grain of the hegemonic heterosexuality that characterizes Ukrainian society. Anton's story below will further illustrate how constructions of hegemonic masculinity—which emphasize men's sexual (hyper)potency and their responsibility to take the "active role" in sex, and assume exclusive heterosexuality—are problematic in the context of disabled men's lives.

Although Dmitrii does draw on elements of hegemonic masculinity in his understanding of what it means to be a "real man," he also has sought avenues to cultivate a new kind of masculine identity for himself through dance and mentoring, for example. For him this is not a seamless process and he is not entirely comfortable discussing issues of masculinity and sexuality (with this female researcher, at least). He often deflects serious conversation by making jokes, and he frequently refers to the "absurdity and paradoxes of life" as a way to steer the conversation. Dmitrii's story is reflective of the multiple and contradictory ways that men with disabilities are positioned in popular discourse (asexual, heroes, hyper-sexual), and the range of possible responses enacted by individuals in particular contexts. In Dmitrii's case, such responses have included simultaneously pursuing strategies to recapture "lost" masculinity by adhering to a certain body culture (intense physical conditioning, sports, striving to "walk again") but also exploring alternate physicalities and visions of masculinity through non-traditional (for Ukraine) wheelchair sports such as dance.

Anton

Anton's story is indicative of ways that gender, ethnicity, and political identity intersect with and inform an individual's experience of disability and disability identity. Like Dmitrii, Anton was injured in 1989. Anton was 29 years old when he was shot through the stomach and back in a rather valiant scenario—on the dark streets of Kyiv he was trying to protect his best friend from men he thought were armed criminals. (They turned out to be intoxicated police

officers.) Anton's official diagnosis is a "gunshot wound to the nerve endings," and he uses forearm crutches. Anton says that when people find out he was shot "they assume I'm a veteran from the Afghan war, a policeman, or a bandit." As a young man Anton served in the Soviet military before attending university and becoming an engineer. Now Anton does not hold a paying job but he receives a disability pension and rents out a second apartment that he inherited from his parents; income from the latter allows him to live comfortably as a single person.

Anton's family had German roots, and as Germans his grandparents suffered in the waves of repression during the Stalin period, especially during World War II. Anton's ethnicity (he identifies as Russian-German) and family history play an important role in his self-identity. He never supported the Soviet regime and he continues to associate disability politics and a disability identity with the (to him) suspicious realm of the "official." He avoids structures of power as much as possible and also distances himself from the disability community. Anton once told me how he greets one friend over the telephone who works with international development organizations on issues of disability rights: "*Kak tam* 'disabled people' (Rus. How are those 'disabled people')?" Anton's use of the English phrase "disabled people" (he does not otherwise speak English) indicates a certain self-detachment from this "group," and also evidences his recognition that "disabled people" is a reified category that may or may not exist in reality but is frequently targeted by various interventions.

Anton was one of the few people I interviewed in Ukraine who espoused a fairly clear-cut affirmation narrative of disability (Swain and French 2000). More than once he referred to his injury as "the best thing that ever happened to me," and he said that he would not go back and change the course of events if given the chance. During interviews and casual conversations Anton often contrasted the lifestyle he led before his injury with the one he now cultivates, and concluded that he is much "healthier" now than he would have been had he not been injured. In fact, he believes that in many ways the experience of becoming disabled "saved" him. Before his injury, according to Anton, he drank and smoked, was a womanizer, and "was obsessed with one thing—sex." His injury and subsequent disability, he said, forced him to rearrange his priorities, and Anton believes he is "a better man" as a result.

Today, Anton practices a rigorous personal program of mental and physical training, and he has developed a focused life philosophy based on the writings of the famous Soviet athlete Iurii Vlasov (1990), one of the key figures through which the Soviet regime promoted development of a "cultured masculinity" for Soviet citizens through sport during the 1950s and 1960s (Gilmour and Clements 2002: 212-215). In his 1990 article entitled "The Confluence of Difficult Circumstances," which was originally written in the 1970s, Vlasov details his own rise to fame in Soviet sport and his subsequent decade-long illness and fall from grace, and he presents a program for developing and maintaining health and youthfulness through mind-body training. Anton re-reads this 20-page article often, and refers to it as "my Bible." Some of the mind-body practices promoted by Vlasov, all of which make up what Vlasov calls the "healing power of overcoming," include positive thinking and belief in oneself, controlling one's thoughts and emotions, dream

work, constant physical activity, and ever-increasing and challenging physical training.

Anton's Vlasov-based personalized routine includes an "early to bed, early to rise" sleep regime, as well as abstinence from alcohol and smoking, and a daily exercise program consisting of meditation, stretching, weight training, and running up to seven kilometers a day. This regime is sometimes interrupted by chronic pain in Anton's legs, a problem that keeps him awake at night and sometimes consumes his thoughts. He tries to rely on mind-body practices to control the pain, but he also began using painkillers two years ago. Despite his struggles with chronic pain, in interviews and conversations Anton gives the impression of being fully in control, and he exudes the self-discipline that he says is necessary for staying in top physical shape.

Anton realizes that living alone and having few material needs are luxuries that permit him to rigorously pursue his life philosophy and physical training. Other men I spoke to noted that one must be a "judicious egoist" (Rus. *razumnyi egoist*) to undertake such total programs of mental and physical training, but responsibilities to family and work often prevent others with disabilities from leading the type of lifestyle Anton pursues. Anton noted that, because he exercises so much and takes great care with his health, other men with SCI call him a "scared invalid;" they think he is in denial of his disability. Anton counters that he has to keep up this strict regime to "maintain his physical function" and retain the level of mobility he has achieved, and especially to avoid "sitting" in a wheelchair.

Anton does not so much stigmatize *koliasochnyki* (Rus. wheelchair users) as much as he argues that, in a barrier-ridden environment such as that found in Ukraine, he is much more mobile using crutches than he ever could be using a wheelchair. On the other hand, Anton is critical of those who do not "work on themselves" as rigorously as he does, and he named for me several men who he thinks could have worked harder not to "sit down" in a wheelchair after spinal cord injury. His life history narratives sometimes approximated what Smith and Sparkes (2004: 621) call the "quest narrative," through which men "meet suffering head on; they accept impairment and disability and seek to *use* it." However, unlike Smith and Sparkes's informants in the United Kingdom, Anton did not use "journey" metaphors in his quest narrative; neither did he talk in terms of "progress" or moving towards a particular destination or goal (such as "recovery"). Perhaps it is because I first interviewed Anton a full 16 years after his traumatic injury, but he seems very content with his life and "where he is" (aside from his struggles with chronic pain). He jokingly noted that becoming an "invalid" at the age of 29 allowed him "to retire early, as I always dreamed to," and pursue his "real passion in life," yachting.

A self-diagnosed *yachtoman* (an invented Russian word, a play on the word *narkoman*, or drug addict), Anton spends all of his free time in spring, summer, and early fall on his yacht at the Kyiv Reservoir. Significantly, yachting is one way in which Anton is separated (and separates himself) from the disability community in Kyiv—yachting is seen as a luxurious sport for anyone, and especially for "invalids," who are stereotyped, sometimes justifiably, as "needy." At the same time, Anton has tried to promote yachting among persons with disabilities, but says that others have shown little interest in the sport.

Anton admits that, unlike Dmitrii, he consciously separates himself from other persons with disabilities; he says he has more in common with the non-disabled. This detachment from a disability identity appears to be part of Anton's philosophy of "independence;" he sees other disabled persons as dependent on the state and on the "rations" they get from advocacy NGOs. He also dislikes the culture of the disability community, which he characterizes (wrongly, in my experience) as "drinking and complaining." Although he does receive a disability pension, Anton usually forfeits other benefits such as free medical care and health trips to sanatoria. Anton could receive medical care at no cost in his local clinic, but he prefers to seek out trusted specialists, for whose services he was willing and able to pay. Anton stresses that he is an independent, self-providing person in need of "help" from no one. He thus pursues the ideals of individualism, initiative, and independence that are increasingly valued as criteria for being a "real man" in contemporary Ukraine, especially in the current transition to a market economy and neoliberal governance. As Elena Iarskaia-Smirnova (2002a: 125) found for some of her male interviewees in Russia, Anton constructs his masculinity around "resisting the power of circumstances and institutions, and delivering [himself] from dependence."

Clearly, a philosophy of independence and "overcoming" are central to Anton's strategies for enacting masculinity after disability, and a generalized narrative of "overcoming" has become prevalent in disability discourse in Ukraine. One weekly television show dedicated to issues of disability and social rehabilitation in the late 1990s was called *Podolannia* (Ukr.), or "Overcoming." A similar program was entitled *Vykhid* (Ukr. "Going Out"), which in the Ukrainian context of inaccessibility, stigmatization, and public silence on disability issues implies similar processes of "overcoming," or "going for it."

The discourse of "overcoming," one that Anton finds personally meaningful, sits uneasily with worldwide disability rights perspectives. Rights perspectives emphasize the traps that tropes such as "overcoming" set—disability and persons with disabilities are automatically positioned in negative, vulnerable terms, and disability is framed as a barrier rather than a meaningful component of identity, a potentially positive attribute, and so on. But before brushing it aside as an outdated and naïve construction, it is important to consider the social and political contexts in which "overcoming" has become a salient narrative in Ukraine. "Overcoming," which emphasizes individual initiative and personal striving, seems a natural product of the transition to a market-based economy and the dismantling of the socialist state (and welfare system) in places like Ukraine. In this context, an historic emphasis on social solidarity and citizens' reliance on the state are rapidly being replaced by the ideals of individualism, personalization, privatization, and independence. "Overcoming" is appealing to people like Anton because it references the individual and his or her potential for action in a society where the disabled have been denied agency, independence, and even personhood.

Adherence to a particular body culture is another key component of how Anton cultivates his own masculinity. Anton is proud of the developed physique of his upper body, and in newspaper photos and television programs about him he is always shown working out on his exercise equipment at home, often bared to the waist. At the same time, Anton does not seem at all

embarrassed or troubled by his atrophied legs. For his computer desktop Anton chose a photo of himself taken by a reporter that shows him sitting on his yacht in shorts and no shirt. Although Anton's face and tanned and rippled chest and arms take precedence in the photo, he is sitting with one leg prominently in the foreground, and with his crutch propped up beside him. One gets the impression that Anton is refusing to let his "better half" be objectified by "hiding" other parts of his body. The photo, I think, shows how Anton seems eminently at ease with his bodily difference, and comfortable in his disability. So although Anton does adhere to some of the body standards of hegemonic masculinity in Ukraine—strength and an athletic build—he talks of his physical training more in the personal terms of maintaining health and mobility than living up to society's standards of "being a real man."

But there was a time immediately post-trauma when Anton was not so comfortable with his "new" body, especially when negotiating intimacy with women. He referred to sex as "the biggest sore spot for any *spinal'nik*," and said, "It is devastating for a man to lose his potential, and with any *spinal'nik* that is the first thing to go." During several casual conversations and over the telephone, Anton described to me at length how he reestablished himself as a sexual being over the course of several years.

The initial part of this history was tied up with his former wife, Zina. Anton was twice divorced at the time of his injury, and he had broken up with his long-time girlfriend, Zina, a few months before the accident. He woke up in hospital to find Zina by his side, and Anton often described how she loved "the role of nurse, savior, and mother" as he became the willing object of her "womanly duty" after his injury. Although Anton and Zina married soon after he was injured, they divorced a couple of years later, probably, Anton suspects, because he no longer "needed" her as he had immediately post-trauma. However, he also said that their pre-injury relationship was based on "little besides sex and orgasms, an inadequate basis for any marriage."

Over the course of several conversations Dmitrii related to me his own explorations of sexuality after spinal injury. In the early period after his trauma, said Dmitrii, he was not able to satisfy Zina sexually. After he realized that, even though he cannot feel his penis, he could in fact have an erection, he began (with Zina, "who already knew me inside out," as he put it) to develop ways to arouse himself with a partner—these involved taking certain positions, using mirrors, and giving sex a more emotional basis than he had previously ("Now I have to see someone's eyes to become aroused"). Today, even though Anton focuses much of his energy elsewhere, sexuality continues to play a central role in his everyday life and in his enactment of masculinity. He has frequent sexual liaisons, and he iterated that, "More experienced and knowledgeable women actually are attracted when they know a man has a problem in this area. Let's not forget that sex is about more than having an erection or not."

Sometimes Anton gives himself injections (papaverina and fentolamin) to achieve an erection with women who "do not suspect I have any problems," but more often he has sought to explore a more meaningful and creative sexuality than he previously enjoyed, and to cultivate "the emotional and more adventurous aspects of sex." For Anton this has meant a subversion of the hegemonic ideal of men as "sexual brutes" who must take the active position; on the contrary, he notes that many of the women who are attracted to him

are “exhibitionists” looking for a more unusual, empowering, and creative sexual experience. Anton (like Dmitrii) indicated that he has had frequent sexual interactions with women with some history of bisexuality, and who thus overstep the dominant sexual norms in Ukraine. So although for Anton sexuality is an important part of his identity as a man, he has cultivated a type of sexuality based not so much on the standards of virility and potency, but more on sensitivity to his partners and a certain letting go of conventional sexual norms.

There are other ways that Anton goes against the grain of hegemonic masculinity, and these transgressions have caused certain dilemmas for him. Several years ago he nursed his dying mother—a caring role that would normally be assigned to a woman—and he lives alone, keeps house for himself, and cooks his own meals. In many ways, as a single man and especially as a man with a disability, Anton occupies an ambiguous gender position—in some contexts he (rather unwillingly) becomes a social female. Anton once told me:

Women don't take me seriously. They see me as a supplement (Rus. *dopolnenie*) to the men they already have in their lives... They tell me all kinds of private details that they wouldn't even tell their best girlfriends... I don't really mind, I actually find it interesting, but sometimes of course it makes me angry.

When positioned as a social female, Anton is assigned more empathy and a greater level of complete trust and intimacy than are most men (Kaufman 1994: 150).

But Anton's status as a man—one very interested in sexual relationships—complicates the role he is assigned by women as a “social female.” He described how in relationships with women he “plays different roles,” as a (sexual) male and a (social) female. Anton noted that many of his serious relationships have been with married women who are seeking from him what they feel deprived of by their husbands—sometimes it is interesting sex, and sometimes it is a sympathetic listening ear. On the one hand, Anton says he is more or less satisfied with the roles women expect him to play, but he also wishes women could see him as a “real man” instead of “just a supplement.”

Anton also admits that the “pity factor” has prevented him from occupying equal footing with his intimate partners. In Ukraine, pity and infantilization are common aspects of popular perceptions of disability. Disabled men in particular are stereotyped as helpless and psychologically vulnerable, and are presumed to have a powerful need to be taken care of by self-sacrificing women. In reflecting back on his marriage to Zina and the way she cared for and protected him after his injury, Anton noted that “pity (Rus. *zhalost'*) figured prominently in our relationship.” Further, he added:

In fact, since my injury all my relationships have been based on pity...Every woman who shows interest in me expects me to be grateful, stick out my tongue, and pant.

Anton said that the women in his life think they are doing him a favor, “presumably because I am helpless and I don’t deserve them.” He said he will never get used to this treatment, and he is very reluctant to accept this role as “grateful dependent” or the “object of charity.”

In this situation, Anton (and several other men with spinal cord injuries I interviewed) has not been able to have the sort of family life he would like to. Like Dmitrii, Anton would like to become a father, and says his medical tests “show it is possible,” but he doubts it will happen since he has not been successful in maintaining long-term relationships with women. According to Anton, he has grown accustomed to having intense yet temporary relationships with women, and he has learned not to plan a future with his girlfriends.

Overall, Anton’s negotiations of manhood and masculinity after SCI have hinged on the important issue of independence. In insisting on his independence—especially physical and financial independence—from others and from the state, Anton both asserts his masculinity in line with hegemonic constructions, and makes a political statement by rejecting the structures of power that govern disability in post-Soviet Ukraine. However, the strong assumption by others—especially those women with whom he has intimate ties—that he is to be pitied, and should be “grateful for their attention,” partially subverts his identity as an independent, “real man.” Anton is left to pursue his interests (such as yachting, and exercise) on his own, and watch women come and go in his life through what he refers to as “my revolving door.”

Conclusions

The case studies detailed here, along with analyses of popular assumptions about men and disability, reveal a complicated picture of how men with disabilities (and particularly spinal cord injury) in a postsocialist, newly capitalist society “find happiness, fulfillment, and a sense of self-worth in a culture that has, in essence, denied them the right to their own identity, including their own masculinity” (Gerschick and Miller 1997: 457). On the one hand, aspects of Dmitrii’s and Anton’s enactment of masculinity do include the cultivation of a type of hyper-masculinity based on the attitudes and practices of hegemonic masculinity; in Gerschick and Miller’s (1997) terms, they enact strategies of “reliance” on norms of hegemonic masculinity. In the popular imagination in Ukraine these pursuits (i.e. sports, rigorous physical training, or a “fixation” on a specific pastime) are often understood in terms of “compensation”—making up for one’s “lack” by seeking to excel in a particular arena. But ethnographic interviews with men after SCI reveal that strategies of “reformulation” (Gerschick and Miller 1997) of personal criteria of masculinity are also an important part of these men’s stories. As noted by Gerschick and Miller (1997: 457), “the gender practices of some men exemplify alternative visions of masculinity that are obscured but available to men in [a given] culture.” It must not be overlooked that men such as Dmitrii and Anton are broadening masculine repertoires (Shuttleworth 2004b) not only for themselves, but for others in Ukrainian society. In a context where societal norms governing the body, gender, and sexuality have historically been top-down, patriarchal, and very conservative, these men’s negotiations with and occasional resistance to hegemonic masculinities provide those around them

with examples of the potentially empowering effects of subverting or overstepping hegemonic norms of gender, masculinity, femininity, and sexuality.

Additionally, analysis of these men's narrated experiences of disability, negotiations with the Soviet and post-Soviet body cultures, and personal experiments with asserting new gender identities in the face of Ukrainian hegemonic masculinity allows for the deconstruction and critique of the medical/functional/tragic model of disability that continues to dominate in post-Soviet states such as Ukraine and Russia (Iarskaia-Smirnova 2002a: 107). The social model of disability has been quite influential for the work of disability rights activists in Ukraine, and there is evidence that legislation governing disability is moving towards a social or empowerment model since it now targets sources of oppression such as unequal access to education and work. However, there is some tension here since, just when the social model of disability (which defines disability as social oppression, and pinpoints disabling political, social, and economic environments) is being incorporated into the Ukrainian disability rights movement, processes of privatization, individualization, and differentiation are also gaining great momentum in the context of neoliberal economic reforms and the revamping of social programs.

For now, it is unclear what the results of the confluence of these discourses—one of which highlights social oppression and structural violence, while the other privileges individualization and privatization—will mean for persons with disabilities in terms of social programs, empowerment strategies, and transformations in personal and social identity. As these processes unfold, they are likely to have an effect not only on how disability is perceived as a personal, social, and political phenomenon, but also on the continued reformation and expansion of the masculine repertoires among men with disabilities in Ukraine. This is especially true as opportunities for entrepreneurship and economic independence expand.

The material presented here illustrates the enormous potential for ethnographic approaches to help us answer more fully Anton's deceptively simple question, "*Kak tam* 'disabled people?'" Anton's and Dmitrii's experiences reveal disabled masculinity and sexuality in Ukraine to be complex phenomena that are negotiated and renegotiated, day to day, in diverse social, political, and interpersonal contexts. Their stories also provide a window onto the variety of experiences among men after spinal cord injury, and the range of possible responses among men with disabilities to changing political, economic and social climates. Although both men emphasize discrimination and highlight the difficulties of being labeled *invalid* and treated as such in post-Soviet Ukrainian society, their stories also include elements of an affirmation model of disability. This is very significant in the post-Soviet context, where public perceptions concerning disability are still very negative, and disability as a subject for scholarly inquiry is entirely new. Most importantly, these men's stories reveal the creative ways in which post-Soviet men with disabilities are broadening masculine repertoires, a valuable contribution to the small but growing body of literature on gender, sexuality, and disability.

CHAPTER 7

'But Rachael was enjoying it too, wasn't she?' A Learning Disability and Sexuality Case Study

Carol Hamilton

Accessible Summary

Service agencies for learning disabled people in New Zealand have policies that say that people who use the service can have relationships. But it is very hard for people when they want to have a sexual relationship. Many staff do not want to help learning disabled people. Sometimes people have sex in secret and do not tell the staff about it. Sometimes staff catch people together. Then there are big problems.

I did some research with staff. I asked them to talk about what happened when learning disabled people are caught together. I wanted to know why staff had problems helping people. This chapter talks about what the staff said. I found that:

Staff worry that learning disabled people do not know what they are doing because they are learning disabled.

Staff worry that bullying is going on and that the man will hurt the woman.

Staff worry that the woman will get pregnant.

Staff find it hard to talk about sex with learning disabled people and parents.

Staff want to help learning disabled men to have sex more than they want to help learning disabled women.

It is hard for staff but it is their job to support learning disabled people. My research found that staff need more help from their bosses to do their job better. Often staff do not get help from their boss. Instead they get the blame. Staff and the bosses need to work together to solve the problem of how to make sure that all learning disabled people have good sex when they want it.

Introduction

The growth of the disability movement and a number of technological advances has opened up new and exciting possibilities for physically impaired people to more fully explore their sexual and intimate lives (Shuttleworth 2002). However, these opportunities hold only limited potential for advancement for learning disabled people without at least some form of assistance. While the majority of support personnel are now largely positive about the idea of providing assistance in the area of sexuality and intimacy, this endorsement has yet to extend to the long-term development of pro-active support practice (Loftgren-Martenson 2004, Murray and Minnes 1994). Services structures designed to assist learning disabled people with daily living continue to treat members of this group as if "they don't have a desire for intimacy", underpinned by a belief that "so long as no-one discusses sex and sexuality, hopefully the individuals with DD/MR will not be inclined to focus on it" (Allen 2003: 127), resulting in inconsistency and fragmentation in

allocation of the resources necessary to meet the material and social requirements for expressions of intimate and sexual behaviour to take place (see, for example, Frawley 2003). As Hingsberger & Tough (2002) note, without significant change in these areas, the emotional and sexual lives of intellectually disabled people will continue to remain compromised.

The lack of systematic planning in relation to sexuality and intimacy support at the wider agency level mirrors the equally pervasive lack of attention paid to issues of gender in relation to support practice, also characteristic of how wider agency service systems work (Burns 2000). At the meta level, learning disabled people are invariably talked about without reference to gender, thus compromising the development of initiatives designed to mitigate how the effects of gender-based differentials might hinder the adoption of more pro-active sexuality support possibilities (Williams and Nind 1999). Still, downplaying these effects at wider levels does not, in practice, prevent issues of gender arising. Research relating to how matters in the area of gender and sexuality are managed on a daily basis by the workers concerned is scant. However two study findings hint at the complexity and tension that surrounds current practice. These researchers note that many workers continue to disregard intellectually disabled women's sexuality requirements, while a significant minority, 44.2 per cent, deem there to be more important issues to focus on when providing assistance to the women they support (Christian, Stinson and Dotson 2001). On the other hand female workers have also been found to focus primarily on male sexual behaviours in order to protect the women they work with (Loftgren-Martenson 2004). As the most significant group of abusers of learning disabled people are learning disabled men and the most frequently abused group are the learning disabled women they live with, focussing on support and sexuality issues in respect of protection from abuse is a clear necessity (D Thompson, Claire and Brown 1997). However, ignoring the complex role of gender within service structures means that resolving the problematic effects of these differentials becomes a far more difficult task. How to bridge the gap between learning disabled people's hopes and dreams in the sexuality area and the delivery of best support practice remains a difficult and sometimes highly contentious question, for which research findings have provided few workable answers (Bazzo, Nota, Soresi, Ferrari and Minnes 2007). Meanwhile, the "complex and rather distressing picture" (Chai 2004) of learning disabled people's quest for friendship and intimate relationships continues to dominate the research landscape.

Research Methodology

This chapter presents a discursive analysis of interview data taken from a research project exploring how learning disabled people in New Zealand are currently supported in their desire for a satisfying and safe sexual and intimate life (Hamilton 2008). Data was gathered from direct support workers and a deconstructive/interpretive approach was used to uncover and track key gender-related effects that lie within the aspiration/support gap identified by research findings (Bazzo et al. 2007). I used this analytical approach for two reasons. Firstly, gathering data of any kind in this very sensitive life area within service structures remains a difficult task for the would-be researcher, as a literature search of the last thirty years of sexuality and support research

attests (Hamilton 2008). These difficulties include recent statements made by workers in New Zealand and elsewhere that suggest that personal factors that they are reluctant to reveal can significantly impact on their support practice in some areas (Chai 2004, Howard and Hegarty 2003). This reluctance to be forthcoming may underpin the noteworthy low rates of return found in at least some surveys of sexuality support practice, while other questionnaires are returned but with questions related to sexuality support left unanswered (see, for example, Christian *et al.* 2001). In addition, analyses of completed questionnaires reveal weightings towards certain kinds of respondents—older rather than younger workers—raising troubling questions about skewed data findings. Further, the prevalence of responses from female workers dominates this data set, another important research difficulty (McConkey and Ryan 2001). More significantly, while research recommendations have remained consistent over the last twenty years in detailing how the rights of learning disabled people should be met in this area, the day-to-day practice of many workers has remained essentially unchanged. These difficulties presented a strong challenge to how this research study was to be undertaken, and how the data collected was to be handled.

Secondly this approach reflects Pilgrim and Rogers' (1997) insightful comment that research undertaken in the field of disability studies could benefit from the adoption of more diversity in epistemological approach. This point resonated well when set alongside ideas about the impact of social inclusionist ways of thinking on support practices in general. Although discussions about the efficacy of using social model inspired frameworks in particular as emancipatory tools are now well developed, policies enacted from within these conceptual understandings have yet to result in the full inclusion of disabled people in the wider community (D Young and Quibell 2000). Nor have these ideas had the outcome of the "real impact on professional practice" (Oliver 2004: 25) that had been envisaged. Implementation difficulties will arise when models of best support practice are based on an *a priori* acceptance of a discrete division between category groups, on which social realist ways of thinking are based. Within the have/have-not binary into which the social interchanges between category group members in euro western society can fall, individuals become mixed up in antagonistic and ultimately unproductive struggles for recognition and empowerment, at which point the complexities that underpin the initial separation of one group from the other become more difficult to pinpoint and harder to resolve.

Further, continuing to focus on the disempowerment aspect of this binary is only to perpetuate the 'impairment-as-deficit' view (Van Houten and Jacobs 2005) that currently upholds the ongoing oppression of learning disabled people (Armstrong 2002). Social tensions inherent in this 'victim' position merely add to the troubles already facing those who are trying to fit social inclusionist ideas into support practices. In this regard, it has been noted that some people including "disability equality trainers have spent their time trying to make non-disabled people feel guilty that they were not disabled" (Oliver 2004: 24). While it is unclear whether the trainers concerned identify as disabled people or not, what the effects might be of offering a fault/blame position to those who represent the non-disabled to work with is unable to be discussed. As yet, implementation of these principles has yet to

close the divide these “omissions and silences” (Apsis, 1999, cited in Armstrong 2002) create between notions of support needed and personal liberation. Finding an alternative theoretical framework from which to undertake this study was a hard task, yet while research findings continued to reflect the lack of support that is reality of the socio-sexual lives of learning disabled people, experimenting with the application of a different way of theorising seemed a task worthy of pursuit.

This chapter is divided into three sections. I briefly outline the theoretical underpinning that provides the basis for analysis of the data I present. I then use a deconstructive analytical framework to interrogate the content of aspects of a sexuality support case study taken from the data (Burman and Parker 1993). Thirdly, I outline an alternative view of how this material might be re-read in the light of the analysis undertaken. Finally, I comment on two support-related matters arising from this study. I present this information as a beyond binary interactive moment that makes available something of the underlying ‘reluctance to reveal’ position noted in the literature data about sexuality issues and support practices. These ‘disclosures’ can be viewed not only in relation to already-uncovered knowledge about sexuality, (learning) disability and support work but also can be seen in relation to the reader’s own knowledge of the wider social impact of these views on the attitudes and behaviours of individual citizens.

Cartesian Dualisms And Systems of Representation

A number of postmodernist-related lines of consideration underpinned the development of the epistemological framework for this study. These ideas theorise notions of impairment effects and disabling conditions from a position beyond a binary view, so to engage more fully with the wider context in which the social circumstances that shape assistive practices in this support area are located (see Corker and Shakespeare 2002). In this regard, Iwakuma’s (2002) insight was highly influential in beginning the process of developing a different way of thinking about sexuality support practices and their implications for learning disabled people. She suggests that both individual and social realist-inspired analyses of disability have followed traditional euro-western, Cartesian dualisms of mutual exclusiveness - that if something is A it cannot be B at the same time. For example, normality will represent a fixed position which assumes that all termed ‘able-bodied’ will have full access to all rights in equal capacity at all times, while disability becomes its global ‘no access to rights’ excluded opposite. For Iwakuma, the rigidity these dualisms promote limits possibilities for enacting fundamental changes to any material practice, particularly when new ways of doing continue to be sought inside of social systems based on the prioritisation of one aspect of the dualism over the other. Cheu’s (2002) description of disability is also highly influential for my argument in favour of using a divergent epistemological framework. For Cheu, rather than (learning) disability signalling either a bodily impairment or a curable, treatable or socially accomodatable condition, it refers to larger systems of representation that engage “how society has defined *what a body can do* as much as what, in actuality, a body can do” (Cheu 2002: 107). This insight decouples the centrality of the concept of ‘the (material) individual’ from epistemic interpretations of how ontological circumstances might be formed and shaped. Thus, it opens up a space to begin to develop beyond

binary ways of thinking about how support interactions between bodies and contextual spaces might be viewed and interpreted.

Working with these two insights enabled a more flexible determination of the terms 'disability' and 'sexuality' to shape the analysis of what support workers are doing in terms of sexuality support and why they might be doing it. Rather than these terms connoting specific and fixed social meanings, they become aspects of a series of larger systems of representation that draw on certain assumptions about how individuals in the euro/western world operate. Implicit in these systems is the premise of favoured and non-favoured power effects, through which the social, material and emotional networks that uphold the concepts 'disability' and 'sexuality' are constantly held in tension (Foucault 1978). For Foucault, intensities of passion command the real-time power these terms create, and in doing so shape certain social ways of doing as appearing to be prescriptively normal, natural, inevitable and consistent over time. In particular, the coercive effects of the power of "shame, disgust and moralism" (Warner 1999: 114) refine certain material behaviours into representations of key 'ideal/normative' interactions that prescribe the kinds of activities "individual members of the group can enact" (Lapinsky and Rimal 2005: 128). However, Foucault's work stresses the fluidity these social ways of doing contain in that, *at the same time*, these connections hold empowering as well as coercive possibilities. For example, (disabled) women are more vulnerable to the negative social effect assumptions related to 'bad-sex' transgressions of 'ideal' representations than (disabled) men. In addition, 'bad-sex' transgressions are never always either more or less negative, but can also produce alternative ways of considering what ideal behaviour might become in a given circumstance.

Research Method

Participants for this study were gathered through personal contact and a call for volunteers made at two sexuality-related training sessions held in the summer of 2006 in a small town in New Zealand. Collecting data in small rather than large town New Zealand was a deliberate research plan. However I record elsewhere the difficulties I encountered in obtaining participants for this project as a result of this strategy (see, Hamilton 2008). Thirteen workers were eventually interviewed, including eleven women and two men. Six people were interviewed as dyad groups, and seven participated in single person interviews. The structure of each interview was slightly different, with question areas covered dependent on the breadth of experience in the position, the areas of support workers were familiar with and the assistance requirements of the people they worked with. Each interview took between one and one and one half hours to complete.

A deconstructive analysis of the transcribed interview data was undertaken using an amalgamation of critical discourse analysis (eg Fairclough 1989) and more interpretive discursive approaches to data analysis based on the idea that "reality, behaviour and subjectivity are always in texts" (Burman and Parker 1993: 6). Both approaches foreground language as the medium through which systems of norms/ideals and their power effects are created, circulated, (Weeks 1988) understood and enacted (Lapinsky and Rimal 2005). Both approaches view linguistic expressions as comprising historical ways of seeing and knowing through which social experiences are

made “available to people to make sense of their lives” (O’Neill and Morgan 2001: 264). Studying the language of the interview data as cultural texts operationalised the exploration of how gender-based power effects worked within sexuality support process, and how the interplay of coercive and empowering possibilities these processes contained shape worker’s support practices.

Analysis

In a prior article I track how a ‘couple doing normal’ notion about sexual behaviour shapes worker’s attempts to provide assistance to a young learning disabled woman who asks for support to be able to sleep with another woman (Hamilton 2009). In this part of the chapter I discursively unpack lines of conversation about a further “incident of a sexual nature” (McConkey and Ryan 2001: 221), involving another two learning disabled people. I unpick how key aspects of the ‘they’re not sexual/they’re sexual’ meta-binary found in the texts as a whole operates within the examples presented, and track how key power effects related to core assumptions of (hetero)normativity, combined with allied axes of social difference related to femininity and masculinity, interweave to drive the support responses outlined.

Close readings of the dataset produced a particular “I’ve heard it all before” (Edley 2001) point of entry through which wider intersections of social meaning related to sexuality and disability formed a coherent ‘they’re not sexual’ meta-discursive assumption. Given the numerous references in verification of this social ‘truth’ as the culturally overriding understanding about (learning) disability and sexuality in euro-western society (Timm 2002), locating this key assumption and its lines of influence was no surprise. However, the fluidity on which this assumption draws could be seen in the examples of occurrences of sexualised behaviour held within the interview texts. These examples, though very few in number, signalled the active influence of a ‘they’re sexual’ negatively weighted binary effect. This flexibility enabled some sexuality-related assistance for a few learning disabled people to be put into place, but only towards assistance for behavioural outcomes that most closely conformed to key assumptions of heteronormativity, consistent with euro-western middle-class values and beliefs (see Warner 1999, in Hamilton 2009, for a breakdown of these key characteristics).

In the short transcript reproduced below, workers talk about an incident involving two people who live in the home they work in. In the lead up to this statement, a worker enters a room to find Stephen and Rachael together. A later comment by the worker concerned—“I was at the clothesline and came back and there they were on the lounge floor”—pinpoints the location of the room within the house.

First Worker: Although didn’t someone say once that Stephen was found romping around... rolling around the, with Rachael. But Rachael was enjoying it too, wasn’t she... but nobody’s actually asked Rachael, no we’ve never said anything about sex.

Second Worker: Well she [the manager] had a talk to Rachael about it and went down to the day-base and explained to her what sex was, and Rachael said “I’m not doing that, that’s disgusting”.

Pinpointing the operation of the meta-binary related to Rachael's position as a learning-disabled woman provides the starting point from which a more specifically gender-related discursive analysis of this 'incident of a sexual nature' and its support practice consequences emerges.

Rachael

In the vignette above, the 'romping around' phrase initially locates what Rachael is doing within a set of circumstances in respect of which it could be said that she is a willing co-participant in what could be described as an essentially enjoyable escapade. At this point, it could also be said that this phrase engages a view of Rachael as a positively disposed, competent and agentic partner in respect of this light-hearted, perhaps sexual perhaps not, occasion. For a moment, the idea that support could be offered to Rachael as a person deemed capable of equal participation in further pleasurable, perhaps sexual, adventures is held open. However, 'romping around' is then exchanged for 'rolling around', indicating that a less pleasurable, light-hearted and co-participatory, and more overtly tension filled and sexualised vision also infuses this view. Any thoughts that Rachael might knowingly have chosen to participate in this interaction disappear in the face of the more disquieting implication her learning disabled status reinforces - could 'rolling around' indicate that Rachael was struggling to get away? The behaviour witnessed is taking place on the less socially favoured lounge floor, instead of in Stephen or Rachael's bedroom. This (more dangerous?) location, coupled with the 'fact' of Rachael's being a learning disabled woman, could indicate that other, perhaps more non-favourable, even abusive, behaviours might also surround these actions. In this location, a less celebratory view of hetero-normative intent, driven perhaps by prior knowledge of the sexual abuse many learning disabled women experience as vulnerable and often uninformed users of services, could inspire this less favourable vision.

Confusion about which aspect of what binary position to substantiate in relation to these behaviours infuses the "but Rachael was enjoying it too, wasn't she?" remark that follows the 'rolling around' descriptor. However, despite the seemingly positive endorsement of what Rachael is doing, the "wasn't she?" question again undermines the capacity for this behaviour to finally be judged as either competent or pleasurable. Resolution of the difficulty in ascertaining whether choice or coercion underpins what the worker witnesses is not sought from Rachael herself at this point, as the "but nobody's actually asked Rachael, no we've never said anything about sex" statement reveals. Yet, as the final remarks made by the second worker show, Rachael is given an explanation about "what sex was" but, significantly, not by the workers concerned but by an agency service manager. It remains speculative as to what kind of information might elicit the "I'm not doing that, that's disgusting" response Rachael is said to have made. However this reply correlates well with research findings that note that learning disabled people often find explanations about sex given in agency settings "embarrassing and irrelevant" (Frawley 2003: 4) to their needs and wants.

Left at this point, these lines of discussion clearly illustrate a lack of depth of engagement with a number of key issues involved in this incident by the workers concerned who, it could be said, elide responsibility for either the positive or negative tensions inhering in the lounge floor incident, in favour of

straight away passing this was-it-sexual dilemma on to a more senior member of staff. However, a later re-visiting of this incident reveals that a wide variety of support outcomes were discussed in a number of places by a number of people, including a meeting of all support personnel connected with this group home.

First Worker: And we all went into sort of [laughs] thinking “God what are we going to do about this?” Cause, you know, Rachael’s been brought up in a very strict [religious] household. So we can’t... you know if we send her home to her Mum for a visit and not, and she sees medication and contraceptive pills on there, Mum’s going to start asking questions of ... It’s the whole family hook-up so we thought we need to talk to Rachael and do we need to put her on the contraceptive pill? In case it happens again and staff don’t interrupt them again in quite enough time.

Workers, far from handing over responsibility to a manager as their first response to what has happened, have actively considered a number of sexuality-related support outcomes. These include the desirability of using “medication and contraceptive pills” as precautionary devices, and also having to negotiate their use with “Mum” and a “very strict [religious] household”. Complex allied axes of social difference related to femininity and sexuality, held within the context of the social power of family, religious belief and duty-of-care related service concerns, spill through the support gap the “we’ve never said anything” statement initially closed over. Rachael and these workers remain mired within powerful, stereotypic representations of women’s sexuality as ever, always and only linked to family and reproductive capacity, thus limiting the potential for the development of more flexible support possibilities to queries about the advisability of the use of condoms as a more feasible support option.

Stephen

Hesitation, uncertainty and what could be said to be a lack of sustained engagement with development of positive outcomes characterises the support responses offered to Rachael. Wider social truths about sexuality that surrounds Stephen’s position “on the lounge floor” and support outcomes held in subsequent lines of talk in relation to further assistance for him are different in form and content. These responses are unpacked and discursively examined through the following statement made by the workers directly after recounting what was seen on the lounge floor.

First Worker: ... but Stephen was very ... Stephen would have loved to have sex. And Stephen masturbated all the time.

Second Worker: it was only when he was in his room and um one of the girls must’ve walked passed his room one night and said to me “Stephen must be hot because he’s got, he’s got no clothes on”. But you know Stephen quite often slept with no clothes on and masturbated all night because you could smell it and that ...

First Worker: ... you could see it on his sheets...

Second Worker: ... only ever did it in his room and he was quite good about it eh. But he, he actually made a, he actually needed to go and visit a prostitute. He needed to have sex.

The open declaration, that Stephen “would have loved to have had sex” framing these statements signals an overriding acceptance of his capacity and agency in regard to any incident “of a sexual nature”, despite his learning disabled label. Validity of this position, reinforced through his stated ability to self-pleasure “all the time”, or at least “all night”, infuses these comments from beginning to end. In addition, certain behaviours connected to key aspects of euro-western, middle-class values related to knowledge of correct procedures and protocols in these matters are presented as additional proof of his mastery of himself and his surrounding environment. Stephen knows what clothing to wear on such occasions and the appropriate place for expressions of these actions, as “only when in his room”, albeit that his door does remain ajar. The length of time Stephen spends on what are deemed socially favoured behaviours, with addition bio-medically related proof provided by the “you could smell it” and “you could see it on his sheets” descriptors, further reinforces this positive overall view. Finally, the “he was quite good about it” endorsement rounds off the appraisal of proficiency that infuses these statements as a whole. In view of the difficulties learning disabled women experience in relation to the men they live with, the “good about it” assurance is necessary. However these remarks also point to a significant, ongoing, perhaps even obsessive, depth of worker engagement with Stephen and issues of a sexual nature. There is no elision of responsibility here. Indeed, a statement offered later on notes that at least some recognition of his entitlement to participate in what are viewed as pleasurable aspects of sexual desire in euro-western culture has already been actioned, and pro-active assistance provided.

Second Worker: I bought him a book once. I bought him one of those S and M male magazines that had all the girls in it. We were going to the supermarket and I said to him I said ‘D’ you want to buy that Stephen ‘Yes, yes’. “Ok, but you’re only allowed to keep it in your room cause the girls might not like it.’ Fine, he was great with it. Loved it

These remarks indicate the enormity of the gap between how Rachael - as one of ‘the girls’ - and Stephen’s (adult?) wants and desires are located and supported. At no point is it suggested that Rachael “would have loved to have sex”. No comparable women’s magazine is offered to her. No favourable, or even otherwise, comment is made about masturbation in relation to her prowess, although it remains an open line of speculation as to whether this aspect of sexual pleasure was discussed during the explanations she received from her ‘talk’ with the manager. Finally, no comment about ‘visiting a prostitute’ is offered as an alternative outcome. Exposing these differences is to reveal the working of a fundamental wider social truth about the (sexual) difference between men and women, relying on a core assumption of men’s sexual need (E Bell 2005) that operationalises a key culturally intelligible fact about how the euro-western world operates. This

common sense assumption ensures that certain aspects of Stephen's 'need' are far easier for workers to comment on and to work with. However, this assistance only extends to access to a very limited, mechanistic set of behaviours that do not address the long-term development of any feelings of sensuality and affection through which these 'needs' are most satisfyingly expressed. Further the 'prostitute' offer is so firmly set within the conventions of hetero-normativity that it is almost impossible to imagine that the person Stephen would be assisted to 'visit' might be a man.

Exploring An Alternative View

While the long-term outlook for key aspects of Rachael and Stephen's socio-sexual development look particularly bleak, the "Stephen must be hot because he's got ... he's got no clothes on" remark attributed to one of the other women who lives in the house, sits at odds with the 'masculine/aware/competent' vs feminine/naïve/ignorant' binary to which subsequent support considerations are fixed. A re-interpretation of 'hot' opens up a new line of possibility. Could the "he must be hot" phrase indicate that this woman is showing an interest in being supported to participate in a sexual experience? Could 'hot' mean that Stephen's behaviour looks like an inviting opportunity to a (sexually) knowledgeable, rather than ignorant, woman? Could the open door suggest that an invitation is being tendered to the women of the house to choose to enter and take part in what is going on "in his room?" As this piece of conversation was reported, has support for this possibility been considered? As nothing more was said it remains an open question as to how far consideration of this implication of sexual competence on the part of 'the girls' in relation to Stephen might have been taken. This point is further unpacked and explored through the following practice example outlined below. This following vignette details how service personnel respond to another incident in which a different learning disabled woman and man have been found together. How the young woman concerned is positioned amplifies the difficulty learning disabled women who live in this service agency experience being viewed as in any way (sexually) willing and competent social players.

We had a young lady that was um being touched by a young man in places yeah in her private places, to her were her private places... in the workplace... She was given counselling for that because she was obviously very distressed about it. So she was given counselling through ACC [Accident Compensation Commission]. She couldn't deal with it because she hadn't been taught or told that if somebody touches you and makes you uncomfortable you are within your rights to say "No, back off", you know? "Get away" or "Don't touch me like that I don't like it", you know?

An overriding assumption of sexual passivity, purity and naivety infuses these statements. In this case the behaviour involved is no consensual romp, but comprises an experience that can only be described as unwanted, if not abusive, of the 'young lady' involved. The "back off", "get away", "don't touch me" and the more explicit "I don't like it" expository phrase reinforces this point while they also uphold the "given counselling" support outcome that follows.

Again in light of the unwanted sexual behaviours that learning disabled women are frequently subjected to (McCarthy and Thompson 1996), this view carries great legitimacy and power. However, while talk of distress remains linked to broader assumptions of innocence, youth and purity, the presence of other allied effects that might acknowledge and support the presumption an active sexually knowledgeable and desiring young woman who would like to be “touched in her private places”, cannot be factored into any support response. That the young woman’s ‘distressed’ reaction might indicate the fear and shame many learning disabled people experience, not so much at a manifestation of sexuality per se, but at the possible negative consequences that can follow discovery of these actions in the ‘public place’ that is this service setting, cannot be considered (McCarthy 2001). That this young woman might be caught between experiencing a touch that is wanted in a physical sense yet is equally unwanted in a wider social sense, which may well engender the powerful yet ambivalent “obviously very distressed” emotional response, seems to remain unnoticed. Finally, within the ambit of purity and innocence these statements convey, it would be very unlikely that the young woman concerned would or could suggest that this incident represented a desired experience, no matter how ‘verbal’ she might be.

These incidents, and many other practice examples outlined by the workers, invariably ended in a no-further-support-necessary position in relation to assistance for a more direct pathway to the development a more satisfying sexual and intimate life for the people involved. Alternative points of view that could open up useful support avenues seemed to lack the social power to finally influence assistive actions, as this comment related to a subsequent group discussion held about the pros and cons of the counselling support outcome noted in the example above.

The day people [support workers] wanted them to actually be together for this so they could talk about it, but I thought that was a bit rough ‘cos she was terribly upset with the situation to start with. And I thought that was asking a bit much.

These final brief comments and the prior circumstances that give rise to them, raises many questions. What needs to change in support systems in order to lessen the impact of the common sense assumption that prioritises men’s sexual ‘need’ as normative, while leaving learning disabled women stuck in the position of naïve and powerless sexual victim? What changes are needed in order to support workers to be able to work more openly with the social effects of this binary in ways that would also be more fulfilling for Stephen and the nameless young learning disabled man? How might a perspective based on the idea of ‘disability’ and ‘sexuality’ as a series of flexible and dynamic power effects, rather than a set of fixed and unalterable social attributes alter the material, social and emotional landscape that currently shape support practice?

Conclusion

Robert (2005) suggests that when generating research studies it is important to try to find ways of making a difference to the position of those who are under review, as much as the position of those for whom research is

undertaken. The research initiative from which this case study has been drawn was designed to provide more information about what is currently happening for learning disabled people in the area of sexuality and intimacy in New Zealand. I discovered that much needs to be done to resolve the current difficulties learning disabled people face; so to secure their right to belong in this culturally sensitive but highly prized life area, I chose to concentrate on reviewing the worker position as the focal point under review. I did this primarily because of their acknowledged influence in the day-to-day lives of many learning disabled people (eg Cambridge and Carnaby 2005, Mansell and Elliot 2001, Treese, Gregory, Ayres and Mendis 1999). Support is critical to learning disabled people's success in the area of sexuality and intimacy, yet this has been a very under-researched area of investigation in this country and more in-depth and detailed information is still needed. However, it is of concern that making visible the discursive power of hetero-normativity through the medium of worker's talk may merely become yet further evidence of the poor attitudes and values workers hold about the learning disabled people they work with (Drinkwater 2005).

As Lamb (1996) notes, the problem with the general tendency to lay blame that inheres in these discourses of individual deficiency is that blaming is not productive, in that it is not possible to both blame and encourage another to take responsibility for their behaviour at the same time. Researchers and practitioners alike need to continue to think deeply and productively about the support issues involved in this area of work, in particular to tease out and resolve the ambivalent position workers can find themselves in with the people they work with. How service organisations are to be encouraged to hire more men to work with learning disabled men in a support role is an issue about which few comments are openly made, but to which much more consideration needs to be given. Moving away from the centrality of individual deficiency as the root cause of support difficulties will enable a deeper understanding of how workers, as much as learning disabled people, are controlled by the social conditions of their (sexual) lives. Within a theoretical framework that encourages a deeper reflection on the outcome of discursive effects, rather than lays blame on the premise of individual malpractice, it becomes possible to explore more fully how to encourage support for the production of beyond binary moments through which satisfying and safe sexual interactions between all learning disabled people and their intimate friends can begin to take place.

PART II

SEXUAL CITIZENSHIP AND SEXUAL RIGHTS

CHAPTER 8

Sexual Citizenship, Commercial Sex and the Right to Pleasure

Teela Sanders

Accessible summary

This chapter is about people living with disabilities (mainly men) who buy sex. It looks at how people with disabilities are treated badly in terms of how they can have relationships with other people, and find other people to have sexual relationships with. We have done some research to look at the different ways that people buy sexual services and have found that:

- Some people use their benefits to buy services from an escort.
- Some men feel they cannot develop 'normal' relationships as it is hard to meet people, so they buy sex to fulfil their needs.
- The Internet has helped people look for sexual services which are right for them.
- Sex is not the only benefit but getting on with the person and making friendships is also part of this experience.
- Some sex workers see a lot of men living with disabilities and are aware of their needs and have accessible flats.
- There are some countries where access to buying sex is easier than in the UK.
- More women living with disabilities need to be asked about their sex lives.

More needs to be done to make sure that people with disabilities can have sex, and achieve the same enjoyment that people without disabilities have. There are some groups which campaign for sexual rights, such as the right to a sex life, just like disabled people have the right to jobs.

Introduction

This chapter focuses on sexual citizenship for people with impairments and discusses the theoretical issues of sexual citizenship in light of some empirical findings on how this is facilitated. The chapter is divided into four sections. First, what we know about the relationship between commercial sex and disability is explored, as well as highlighting some of the problems associating a marginalised group with a 'deviant' sexual activity. Second, findings are presented from a study which uncovers the relationship between disability and the sex industry. The focus here is on men who buy sex, sex workers who provide sexual services and how the sex industry can meet sexual 'needs'. The third section looks at the wider debates about sexual citizenship and the rights of people with disabilities to access sex. The final section examines a framework for sexual rights and sets out some clear pathways of how sexual citizenship can be obtained.

This chapter does not seek to promote the idea that commercial sex is the only way in which people with disabilities can access sexual relationships. The premise for airing these findings from studies in the sex industry, are to highlight what is currently taking place in relation to people (mainly men) with

disabilities accessing sexual services in a commercial context, how the sex industry is, or is not, equipped to respond to these requests, and the wider issues of sexual citizenship for people with disabilities. At the forefront of the discussions will be the disabling social world which contributes to the reasons why commercial sex can be a choice for those who want to ensure their sex life is not abandoned in the face of a disabling world.

Note that some of these themes and findings have been reported in *'The Politics of Sexual Citizenship: Disability and Commercial Sex'* (Sanders 2007).

Sexual Expression and Disability

Examining the issues relating commercial sex to disability is controversial. The topic does not only deal with the hidden taboo of sex, but deals with the double taboo of the supposed deviant activity of paying for sex and also the even greater taboo area of people with disabilities having sex. There are problems and dangers with connecting a group of often excluded and unfairly treated people with an activity that is equally considered to be for the social misfits who cannot find regular 'normal' sexual relationships. These connections can reinforce the idea that people with disabilities cannot form relationships that are considered conventional, and that therefore they can only find sex if they pay for it. The trap of consigning people with disabilities to the status of 'doubly deviant' is certainly not what this paper is about. Instead, it offers insights into the relationship between the sex industry and men for whom buying sex is a lived reality. It is also an area which is increasingly brought into the politics of prostitution through the current UK government reviews and new legislation.

The little that we have come to know about disability and commercial sex is through media reports and often sensationalist accounts. In the UK in 2008, 'Helen House' hospice for children featured a televised documentary by a young man called Nick Wallis who was living with muscular dystrophy and did not want to die without having a sexual experience. So at the age of 22 his carer arranged (with the consent of the hospice) to hire a sex worker for a two-hour session. In August 2008, the tabloid newspaper, the Daily Mail, printed photographs of four male residents of a private care home (all of whom were living with Huntington's disease) who were taken by their carers to visit a lap dancing club. The care home had a strict policy of ensuring that the recreational choices of the residents are taken seriously and facilitated as much as possible. Further the advocacy group, The Outsiders, campaigned against proposals in the Criminal Justice and Immigration Bill, 2008 which would restrict the civil liberties of people (including disabled people) from enjoying the freedom to pay for sex and download pornography. A Liberal Democrat Lord discussed the work of the Outsiders in the House of Lords, whilst debating the proposed legislation that would seriously limit the way some men accessed sex workers. In February 2008, the Outsiders arranged a legal demonstration on Westminster Bridge to campaign against the proposed new legislation that would prevent legal access to purchasing sex.

There is an international context in which evidence can be gathered that demonstrates how people living with disabilities are customers of the sex industry. In October 2005 Torben Hansen, a Danish man with cerebral palsy, took his local authority to court because he had to pay extra money for a sex

worker to visit his home due to the poor access to the brothel. In Switzerland, the organisation Fabs has provided erotic massage and other services for people living with disabilities for some years. More details about the facilitation of commercial sex can be found in the Chapter by Wooton and Isbister which documents the rise and activities of the Australian organisation 'Touching Base' who have supported sex and relationship facilitation for several years. There are few examples of the state intervening to provide or support commercial sex for disabled people. The exception is the Netherlands where sexual assistance has been provided by the state for 30 years.

The Role of Commercial Sex

The findings in this section are taken from two empirical studies which focused on wider issues relating to commercial sex, sexual politics and the organisation of sex work. The first study was a ten month ethnography of female sex workers who worked from the indoor sex markets in the UK (Sanders 2005). I observed the working lives of women who worked independently in flats, from illegal brothels, massage parlours or as escorts doing outcalls to men's houses and hotel rooms. In this study I interviewed 55 individuals involved in the sex industry (50 sex workers and 5 people involved in managing premises). The focus here was on the risks that sex workers faced, their own meanings attributed to the daily routines they experienced and how their working lives affected their personal lives. The second study investigated the other side of commercial sex: men who purchase sexual services (Sanders 2008b). Here, I interviewed a self-selection sample of men who responded to an Internet advert and a radio interview about the project. Fifty men were interviewed about their experiences of buying sex, how this fitted in with their lives and relationships, the emotions they felt and how they managed stigma.

As a result of these findings, which did not specifically seek to ask questions about the relationship between disability and commercial sex, there was a strong theme amongst both the sex workers and the male clients regarding the centrality of disability to commercial sex. For instance, sex workers volunteered information about how many male clients had disabilities and how they adapted their services and facilities to provide access to this group. Equally, five men who volunteered to be interviewed for the second study had impairments, which gave great insight into how they engaged in commercial sex to achieve sexual needs that were not being met. The limitations of making generalisations are significant given the small number of respondents in this specific category. Nevertheless, these triangulated findings from two separate projects indicate that intersections between disability and commercial sex are present in the everyday lives of individuals.

Men with Impairments Purchasing Sex

We already know something about the relationship between disability and buying sex. The *Disability Now* 'Time to Talk' Sex Survey (2005) included a specific section on sexual services, alongside other sections inquiring about sexual activity, sexual well being, sexual abuse, sex education, sexual health and sex and disability. 11.7 per cent of male respondents indicated that they had visited a sex worker. The *Disability Now* Survey provides new information on the high prevalence of men and women who had considered visiting a sex

worker. 37.6 per cent of men and 16.2 per cent of women had considered commercial sex as a viable option to meet their sexual needs. With no statistics from the general population, it is hard to make any comparisons or surmise whether people with impairments consider buying sex more or less than non-disabled people. A further two-thirds of the respondents said they would consider commercial sex if there was a legally regulated service. Amongst the survey respondents, there was considerable support for legal change: 75 per cent said yes to the question "Should prostitution be fully legalised?" This support for legal change to enable prostitution within the law is very pertinent given that at the time of writing the government are considering introducing a new law which makes it a crime to purchase sex.

The literature on men who buy sex documents the range of motivations that men have for buying sex. Brooks-Gordon (2006) reviews the range of theories which explore the motivations for buying sex including: the desire for different sexual acts, sex with different types of women, loneliness, relationship breakdown, mobility (travel for work and leisure), promiscuity, and even psychological difficulties. There are a myriad of reasons why men buy sex. Amongst the men who spoke to me in study two, the motivations were not necessarily different from the general theories on why men buy sex. For example, Alastair, a 59 year old man with a physical impairment which had left him with restricted movement in his legs, has visited over thirty sex workers in the last year. He now regularly visits three sex workers with whom he has found a rapport. His initial reasons for seeking sexual services were because of a life of unwanted celibacy which he related to his lack of self-esteem:

Because I'm not very big, I'm only 5 foot 4, I've got small hands, small feet and small something else. I'm not your alpha male and so tie that in with my own insecurities, I guess sex has always been difficult. I've been told off by one of the women I see fairly regularly because I use the phrase "a bloke like me" because I walk with a gammy leg, I've got quite a pronounced limp. I have quite a low self-image and I thought hey even a bloke like me can do this [commercial sex]. It was a matter of feeling in inverted commas 'normal' because remember I'd been celibate for about 16 years. It's a bit like taking a driving test, I was alright on the theory but it's coming to the practical. You're out of practice.

Inexperience of sexual relationships is another popular reason for men seeking out sexual services which can be purchased within the confines of a commercial relationship. Some interviewees expressed a genuine stigma or concern about being an 'inadequate' lover because of physical impairments and a lack of knowledge or practical experience of doing sex. Alastair comments:

Well there's no point in hiding it. Basically I'm not very good at sex. I don't become aroused for long enough. I'm not very good at penetrative sex because, I mean if you saw me from the age of about 11 to the age 17 I was in callipers from groin to heel on my left leg, so I can't bend my left leg.

The disabling factors of the social world because of restrictions on forging relationships, visiting places and spaces where relationships are facilitated and engaging in normative social activities, is a major barrier for men with disabilities. Stuart, a 36 year old man who has lived with a visual impairment for fifteen years, makes specific connections between the structural discrimination of not being able to find suitable employment, financial difficulties and a distinct lack of social life:

I was seven years unemployed, because basically if you've got a visual impairment in the job market you just can't succeed. I didn't have any money... I couldn't go out, I didn't go out. I couldn't meet other people but since working I have met other people as well as seeing escorts.

However, it is important to remember again that the motivations for men seeking sex are universal, whether they have impairments or not. A point I have argued in my other work is that for some men purchasing intimacy and emotional aspects of a physical relationship are as important as the sexual aspect (Sanders 2008a). Paul, a 44 year old ex-builder who now uses a wheel chair after an accident at work, has been visiting sex workers for three years and describes how sex is not the only outcome:

You know it's wonderful to feel flesh on flesh when you haven't felt it for years. And quite apart from anything else, I say the two women [sex workers] I seen most often I don't always have penetrative sex with and I say to them that in one sense if that does not matter because I'm enjoying being with them. We have what the Irish would call the crack, and we talk and share things. Like this woman I saw yesterday, she likes the same music as me so we listen and appreciate that together. I don't want it to get any closer than that. But just to know that there's that sort of link as well – it's nice.

Men with impairments who I interviewed as clients of sex workers spoke readily of the social nature of their relationship with sex workers:

I go for two hours rather than one because you can sit down and have a chat, you know, be a bit friendly, chatting about what's happening in the world and what's happening in your life. The girls I have chosen have been really good to me... it's also just the fact that you're having a chat like a bit of companionship because I'm a single lad and you know sometimes you just want to talk to a woman. You can talk to your friends but its different talking to a woman.

Becoming a regular client is a key theme of a proportion of men who buy sex (see Sanders 2008a). Men who repeatedly return to the same sex workers do so because of the familiarity in both the bedroom and the social encounter. Building up a rapport and finding a sex worker with whom they feel comfortable and have points of interest was as important for some interviewees as the physical attraction.

Simon explains how missing out on important years of his life because of his impairment meant that at the age of 29, his sexual status was unsatisfactory:

I got disabled when I was about 19, so it took us a couple of years to get over the shock and trauma and then I was unemployed. So the normal basics for most teenagers, say under 25 is you get yourself a job or go to university and socialise. Well frankly, that didn't happen to me... I was 29 and a virgin and I had a compelling wish not to die a bloody virgin... at least now I won't be bloody petrified with a girlfriend and think what do I do now... I mean I'll be able to negotiate that a bit more easily.

There are other social benefits that were reported as a result of being part of a wider sex work community. One man reported communicating with men and women through internet chat rooms and message boards enabling interactions in the virtual communities on a daily basis and promoting feeling part of a 'community'. Derek, 42, explains how communicating online has become a regular and important part of his social networks:

I spend at least an hour a day reading and replying to posts. There is a lot to take in... it is just somewhere to go where you can express opinion and you know you're with, well like-minded people. It's a community. I have got to know a fair few people through cyberspace. It's not real, it's not the same as having real friends but they are like virtual friendships really. But we do meet up, us that lives in the North. I have been to three parties that have been arranged.

Men who spent many hours online reading and posting contributions to message boards and taking part in the virtual community found that there was a real benefit to finding social support. These relationships did not remain 'virtual' but sometimes developed in to real-time friendships where relationships were open with regards to buying sex. Meeting in public, either in couples or a larger social group, was not an uncommon experience.

The question of payment in relation to sexual services is one aspect of the dynamic regarding financing care and what the state should be obliged to pay for. While disability benefits and provisions of 'care' in the UK do not take into account facilitated or commercial sex costs, individuals are making their own decisions about their needs and how their entitlements should be spent. Simon explains:

My punting money, £200 every month or whatever comes from my Disability Living Allowance and my working tax credit. Before I was working, my care component and my Disability Living Allowance went on seeing girls... this is for your care needs. It's up to you as an individual to determine what those care needs are. I would imagine there are a lot of disabled people out there who are using part of the DLA money for punting.

It seems that individuals are using their agency to make financial decisions about what type of provisions will enhance their quality of life. Shakespeare (Shakespeare 2000: 161) reminds us that “being sexual costs money”. The key question for further research and commentary is where is the money coming from?

Providing Sexual Services

The first study encountered women who described their relationships with men who visited them to buy sex who also had disabilities. For some sex workers, this group of men comprised a significant proportion of their clientele.

Below Ava and Krystal, who had worked together in a sauna for ten years, relay anecdotes of providing sexual services to men with physical disabilities:

Ava: I have lots of disabled punters. Like one regular, he was able bodied and then became disabled. It is a big thing and he tells me he feels inadequate with his wife so sex does become an issue. Because they are paying us for the service it takes away their responsibility and stress that surrounds sex. They are just human, they have got an urge and a need and in fact they are less demanding.

Krystal: Half of the time it is not the sex it is just another human contact they want. Just being with another female. Sometimes you don't even have to get undressed because they want other services, or someone actually putting their arms around them.

Ava: Like in the sauna, there was this man who couldn't walk and his carer would bring him. You had to lift him out of the wheelchair and into the jacuzzi and he was stiff because he didn't move his arms and legs. He couldn't move, could get an erection but that was about it. He could not move, or talk or anything. We used to go to this warden-controlled place to do the ones who were bed ridden. That was normally just hand relief.

Krystal: It is care in the community. I look at this as an extension of my job as a nurse.

This exchange highlights the complexities of the relationships men have with sex workers and demonstrates how the emphasis is not always on sexual release as the main component. In addition, this exchange echoes the sentiments of the men who buy sex in so much as their desires are not just motivated by physical release but more holistic interventions and communications. The sex workers felt they were providing a function in society specifically to men who were not able to engage in a conventional relationship, including men with physical or sensory impairment (Sanders 2006).

Sex workers who had employment experience in nursing and caring professions rejected the stereotype of 'disabled' people as asexual and the majority did not show disgust at their sexual desires: “We are not just here for able bodied people. Disabled people - they still need to be relieved. It doesn't freak me out at all, it is because of them that I think it has to be legalised” (Kelly, sauna). They were also more matter of fact about sexual acts and had

little reservations when a 'carer' had to be present to assist a person with positioning or technique. From the sex workers accounts, it is not uncommon for 'carers' to bring men to sex work venues and help in enabling the service to continue, or facilitate access to commercial sex for those who live in institutions.

There was also evidence amongst the sex workers that there was the need for specific training regarding providing services to men with different kind of disabilities, and also to be more aware of disability rights. Tracy worked in a sauna and an apartment and explains how her first encounter with a man with severe physical disabilities was a little overwhelming:

I used to have a regular client who was in a wheelchair and couldn't move his arms or legs. It was horrible because you don't know what to do at first. The carer brought him and took him out of his wheel chair and put him on the bed. He had hand relief and oral and I had to move his hands to touch me. And when he went home he had got a computer and he can touch the buttons and his carer called me back up and said that Jamie really enjoyed it. Getting used to speaking to him through his computer was strange, but we did it and he came to see me for about 18 months. Another man came to the sauna in a wheelchair and he wanted to be lifted into the jacuzzi which took a couple of us and it was hard. We needed extra help really as we didn't really know if we were lifting him right.

One sex worker mentioned the frustration of not having any support from disability rights organisations and felt there was an absence of information, and that commercial sex had not been taken seriously as a 'rights issue':

I do not promote my service to organisations although I did have some conversations with SPOD (The Association to Aid Personal and Sexual Relationships of People with a Disability) after their television programme about sex workers and people in wheelchairs. I got in touch with them and said I would like to have some training. They did not seem to be able to provide any information and when I got a call from a disabled guy I was terribly unprepared and I was afraid of doing the wrong thing. But if I found another organisation I would certainly want training or information.

Increasingly sex workers design their service so it is accessible to clients with physical impairments. This is notable on advertising websites that highlight accessible venues with facilities such as easy parking, ramps or lifts, downstairs bedrooms, bathrooms and handrails. Melinda describes how she specifically looked for premises that were accessible for wheelchairs:

That really was one of the reasons why I took this flat, as before I was in a flat with stairs. All the other flats I have been in, other people's, they have all had stairs. I have only seen two people in wheelchairs and both times the carers and I pulled them up the stairs. There is no dignity there. So here I thought I would be set up to deal with mobility issues.

It is clear that some sex workers are very aware of the specific needs of men with impairments and how the disabling world means their access to sexual pleasure is limited. However, more legitimate and coherent organisation for those wanting to access the sex industry safely is hampered by legal constraints, the lack of political will to recognise voluntary and consensual commercial sex and a government agenda which insists on the eradication of prostitution.

Sexual Citizenship and Disability

To make sense of the choices and sexual activities of men living with impairments, the wider context of sexual citizenship needs to be understood. According to Plummer (1995: 151) sexual citizenship means “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”. Sexual citizenship has been a vehicle used by groups that are experiencing oppression because of their social position, status and identity. Feminist, black and gay lobby groups have all used sexual politics as a mechanism for asserting their difference and, at the same time, to assert their rights to sexual expression, identity, feelings, experiences and pleasure. In this way, sexual rights, have been the coathanger on which the right to access sexuality has been fought.

The backdrop to this is that sexual culture, sexual norms and values are constructed on the assumption of heteronormativity – that is that people will exercise standard, traditional male and female roles. The notion of ‘sexual scripts’ (Gagnon and Simon 1973) demonstrate how sexuality is constructed around normative ideas of how men and women will act out their sex roles, performing to a set of behaviours, identities and interactions that are fixed on the notion of abled-bodiedness. This means that for many people their own ‘sexual citizenship’ is never an issue or even vaguely something to consider because it is an assumed norm: most people do not have to think about where they can go to find romance, flirting, casual sex, build relationships, engage in dating etiquette, for instance. Barriers to being sexual are widespread for people with disabilities – relating to socialization, segregation, sex education, physical barriers and exclusion from social environments where dating takes place. “Socio-cultural impediments” for people with impairments stem from isolated experiences as adolescents, parental over-protection and social attitudes relating to body image and cultural ideals of attractiveness (Shuttleworth 2000). Masculinity is experienced differently for men with disabilities: “Disabled men do not automatically enjoy the power and privileges of non-disabled men” (Shakespeare 1999b: 61). This has a significant affect on how sexual citizenship is experienced for men living with impairments.

Limitations on sexual citizenship are embedded in cultural norms. Normative sexual scripts include specific and defined notions of how individuals will engage in sex, what they will look like, their body image, where these spaces for sex and relationships take place etc. It is this level of the social construction of the sexual being which is the starting point for discrimination against people living with impairments. Literature has established firmly that people with disabilities are constructed as asexual, unattractive, dysfunctional socially and sexually, unable to form relationships because of their disability, and have an inability to express healthy sexuality.

Shakespeare *et al* (1996) and Deepak (2002) identify how the barriers to being sexual are widespread, relating to socialisation, segregation, sex education, physical barriers and unclear employment contracts with personal assistants regarding their role in facilitating sex. Brown (H Brown 1994: 123) describes how the models of normalisation that seek to integrate people into society are permeated with a “coherent vision of ordinariness” that includes “an ordinary sexual life”. This ideal of ‘normality’ is in itself prejudicial against people with impairments (amongst other marginalised groups) as there is no acknowledgement of difference in sexuality, sexual activities, identities or relationship formations. Shakespeare *et al* (1996) exposes how people who live in institutional settings are banned from having sex, gender segregated, prohibited from marriage, not given adequate sex and relationship education. Some of this has been because of a concern about the supposed vulnerabilities of people with learning disabilities specifically to abuse and questions over their ability to give consent (see Chapter by Holomotz). These are used as justifications for discriminatory policies and the continuation of prejudicial attitudes.

Sexual citizenship has been successfully used by other marginalised groups to assert their rights: gay lobbyists have campaigned for their rights and contested the heteronormative basis of social spaces, particularly leisure spaces. The gay lobby has been very successful in fighting for the rights of gay people, but the demarcation of specific ‘gay areas’ in the night time economy—such as Manchester’s gay village and similar places in most cities—shows that the desire or ability to be inclusive is limited. While there are problems with geographical ghettos and zones, they do offer a space and place to respect difference. In this regard a recognition of different sexual identities and politics as an integral part of the urban landscape where behaviors can be performed without discrimination is more achievable than any major changes in the heterosexual norm.

It is this backdrop of discrimination and exclusion that some disabled activists have adopted the sexual citizenship concept as a vehicle to assert rights, change and avenues to sexual experiences. For disabled groups, the concept of sexual citizenship has been an important tool on which their own feelings about their sexuality and the discrimination they face can be articulated. It is the rights based framework that has been adopted as a means to speak out against sexual oppression.

A Framework of Sexual Rights

The United Nations Declaration of Human Rights falls short of stating that individuals have a right to a sex life as a human right, but some argue that the right to a sex life is covered under the right to health and well being. The World Health Organization (2004) makes clear links between sexual fulfillment and mental and general well being. The World Health Organisation defines sexual health as: "The integration of physical, emotional, intellectual and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love." Having access to a sex worker can be the only way some people can achieve this integration. To deny a person this, or worse - to make them out to be a criminal, is an abuse of their human rights. The WHO also establishes how “the sexual rights of all persons must be respected, protected and fulfilled” (World Health Organisation 2004). It is with

this sentiment that the right to sexual citizenship is a challenge for those living with disabilities. In this regard specific changes are necessary for sexual citizenship to be facilitated:

- 1) The normative concept of sexuality needs to move beyond the male heteronormative cultural ideal to include other forms of masculinity and of course female sexual citizenship.
- 2) Access to a full social world includes 'access to pleasure' (Tepper 2000b).
- 3) The right to engage in sexual activities, whether commercial or not, should be part of the challenge against the disabling effects of the social environment.
- 4) Commercial sex should be legally facilitated in a safe environment and removed from any underworld, or unregulated economy, in order to take away the stigma and prejudice afforded those who engage in paid for sex.

Plummer (1995) and Weeks' (1991) pioneering sociological observations on the relationship between the social and sexual selves should be applied to understanding the relationship between sexuality and disability. Sexual stories are intricate to people's sense of self, as self-identity is connected very tightly to sexual identity. Structural and ideological straight jackets around sexuality affect our sexual stories. The heteronormative masculine lens through which sexuality has been restricted poses problems for those who do not fit into this ideological framework – those problems extend to harassment, violence and discrimination.

The role of the sex industry is significant in moving forward the sexual rights agenda for people living with disabilities. There are practical changes that can be made to facilitate sexual citizenship, as I have argued elsewhere (Sanders 2007):

- Good practice guidelines for sex workers that are constructed within a disability equality framework that provides information about designing a service for people with mobility and access issues.
- Collaboration between disability rights organisations and sex work organisations to provide training for sex workers.
- Research into moral, social, practical, financial, legal and emotional dynamics of buying a sexual service for people with impairments.
- Research amongst personal care assistants, social and health care workers to find out more about the extent to which facilitated commercial sex happens and the issues for the professionals.
- The *Disability Now* sex survey reported that 16.2 per cent of female respondents had considered commercial sex as a viable option to meet their sexual needs. The needs of women living with impairments are an essential part of this agenda and usually overlooked as their right to sexual citizenship is tied up further with questions of "appropriate femininity" (for a discussion see Shakespeare 1999b: 55).

Sexual politics are at the heart of the discussions about commercial sex and disability. The campaign for sexual citizenship is part of this and needs to be advanced alongside other rights to live an inclusive life and full citizenship.

CHAPTER 9

A Sex Worker Perspective on Working with Clients with Disability and the Development of Touching Base Inc.

Rachel Wotton and Saul Isbister

Accessible summary

In this chapter two sex workers, Rachel and Saul from Australia, talk about their experiences of providing sexual services to clients with disability. Between them, they have over 34 years of sex work experience. Here they share personal insights and stories which provide a greater awareness and understanding of the range of issues and barriers that sex workers, people with disability and third parties (like parents or carers) may face when arranging a sexual service. In this chapter they:

- Discuss privacy and confidentiality issues
- Explore how the attitudes held by some disability organisations or individuals towards sex workers may act as a barrier to equal access to sexual services.
- Challenge the myths that people with disability are asexual or only heterosexual.
- Describe how services may be adapted to meet the needs of clients with communication and mobility impairments.
- Examine the essential roles that mutual respect and trust play in creating a safe environment for all parties
- Discuss financial limitations.

The authors describe their involvement with the photographic exhibition *Intimate Encounters*. This exhibition challenges the usual stereotypes of the sexuality of people with disability.

This chapter also outlines the creation and development of Touching Base Incorporated (Touching Base), an organisation which brings together sex workers, people with disability and service providers working in the disability sector. In 2000, when Touching Base was first established, the Australian state of New South Wales (NSW) was the only jurisdiction in the world where sex work was decriminalised. The enabling environment created by decriminalisation permitted open discussion between all stakeholders without the threat of criminal sanctions.

The two main reasons that Touching Base was formed were:

- Sex workers' desire for training to better meet the needs of their clients with disabilities, and
- The needs of people with disability to find willing and experienced sex workers whom they could trust to meet their needs.

Since 2000, Touching Base has been involved in a wide range of activities including:

- Researching the attitudes of disability service providers towards supporting people with disability to access the sex industry.
- Marching in the annual Sydney Gay & Lesbian Mardi Gras Parade.
- Creating an accessible website to provide information, support and resources.
- Developing training workshops for sex workers, known as Professional Disability Awareness Training.
- Developing training workshops for disability service providers, known as Service Provider Awareness Training.
- Creating a specific referral list of willing sex workers, and accessible sex industry establishments.
- Presenting at numerous conferences, lectures and workshops.

The authors are currently involved in research. Rachel is conducting a survey of NSW sex workers who provide services to clients with disability. Saul is doing interviews with men and women with cerebral palsy who have accessed sex workers.

The authors hope the results of their research will be used to further promote the sexual and human rights of both sex workers and their clients with disability both in Australia and elsewhere around the world.

Stepping into the unknown and finding pleasure

I'd never met Peter before. It's was only as I walked towards his darkened house and tried to find the hidden key that I fully realised how much trust had been invested in me. I found my way through the house guided by his voice in the bedroom and both of us were fairly nervous as I turned on the light. Half an hour earlier Peter's carer had tucked him in to bed for the night, leaving Peter's credit card in the top drawer as prearranged on the phone, another layer of trust. This was his first time seeing a sex worker but Peter's sexual desires were no different to the majority of clients I see. I did, however, meet an unexpected challenge when it came to helping him to undress, due to the rigidity of his lower limbs and limited mobility of his arms. When setting boundaries for this session, we had a little laugh when we agreed that, due to unpredictable spasms, it would be unwise for him to perform oral sex on me.

Introduction

In this chapter we present our collective reflections related to sex work and disability. Based in Sydney, Australia, but having worked as sex workers in numerous locations around the world, we aim to share elements of our personal journeys that have led us to embark upon an academic career within the emerging field of sex work and disability. We are not speaking on behalf of all sex workers; however through our many conversations with other workers over the years we have found that our experiences working with clients with disability generally parallel those of our peers in the sex industry. The human and sexual rights of both sex workers and people with disability have often been sidelined and ignored. Both groups have been marginalised, experiencing the negative effects of inadequate consultation on issues and

policies that relate to us directly. Failures to listen to affected communities often leads to increased levels of stigma and discrimination. By stepping into the void and speaking openly and candidly on this topic, we hope to illuminate many of the issues and barriers faced by both sex workers and people with disability when they try to meet.

Our approach is consistent with working definitions discussed at the *International Technical Consultation on Sexual Health*, convened by the World Health Organisation in 2002. According to this group of experts, sexual health:

requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled (World Health Organisation 2002).

The clients with disability we refer to in this chapter are all male. This poses an obvious limitation in identifying issues specific to the female and transgender clients of sex workers. These client groups are not frequently discussed or recognised in most literature, legislation or research. We feel it is important for us to acknowledge them here, as we support their rights to freedom of sexual expression, as equal to that of men.

The potential challenges for both clients and sex workers, when connecting with one another, largely remain the same regardless of sexuality or gender. Saul's experiences working with male clients help dispel the often held assumption that people with disability accessing sex workers will only seek heterosexual contact. The assumption of heterosexuality has been well identified as an additional level of discrimination faced by some people with disability who, due to their sexual preferences, may encounter extra barriers to sexual expression (Earle 1999, Fraley, Mona and Theadore 2007, Shakespeare *et al.* 1996).

In addition, it is often assumed that people with disability are asexual (Earle 1999, Shakespeare *et al.* 1996, Shildrick 2004). However, in our experience, clients with disability seek the same range of sexual services as our other clients, including forms of intimacy that may or may not include penetrative sex. In fact, client's physical limitations often lead them to creatively explore alternative ways to experience sexual pleasures. Rachel's experiences with clients with limited "normative" sexual function demonstrate that "where there's a will, there's a way". These men have discovered that they can experience heightened sensitivity and arousal from the stimulation of non-genital erogenous zones. They have recognised that "sex" is not dependant on having an erect penis and that, in fact, the brain is the body's most potent sexual organ. As Shildrick noted, "loss of sexual function is not the same as having no sexuality" (2004:135).

Seeing clients with disability - a sex worker perspective

Saul is an independent male sex worker in his mid forties, who offers male-to-male sexual services. Over the last 19 years he has seen clients living with various impairments including: paraplegia, acquired brain injury, amputation, hearing impairment, HIV, HIV-related dementia, cerebral palsy, intellectual

disability and Parkinson's disease. He has also worked with a number of clients with significant scarring due to burns or multiple operations.

The first time I saw a client with disability I was totally unprepared. No one told me my client had a spinal cord injury so it was hard to hide my surprise when he answered the door in a wheelchair. At that moment I drew upon unknown levels of professionalism to mask my ignorance and fears as I had actually never even had a conversation with someone in a wheelchair, let alone had sex with them! This client acted as a great guide as he took the time to explain how his injuries affected his sexual function and reassured me that I wasn't going to "break him". This marked the beginning of my journey into the world of sexuality and disability.

Rachel is an independent female sex worker in her mid thirties. Having worked in most areas of the sex industry in the last 15 years she now prefers the freedom of working for herself. The majority of her clients are male. Over the last eight years she has enjoyed seeing an ever-increasing number of clients with disability. These include men with a range of impairments including cerebral palsy, acquired brain injury, Parkinson's disease, paranoid schizophrenia, hearing impairment, quadriplegia, paraplegia, dementia, intellectual disability, hydrocephalus and debilitating skin conditions.

Never in my wildest dreams would I have thought, as I walked into my first brothel all those years ago, that later I would end up quietly walking into a nursing home on a weekly basis providing sexual services to someone who can only barely move one arm. It gives me great joy in putting a smile on my client's face but it also saddens me knowing that for him – I may be the only person in his life who touches him for pleasure's sake. His only other contact with people is when they bathe him, take his temperature, dress him and transfer him to a wheelchair.

With over 34 years of combined sex work experience, we have been involved in a range of advocacy and lobbying activities focused on sex worker rights in Australia, New Zealand and internationally. In the process we have become well versed in relevant legislative and policy frameworks, with a strong focus on applying the principles of social justice and better practice within our industry. We have also been willing to engage with the media and an expanding network of professionals, including doctors, nurses, counselors and therapists working in the field of sexual health, along with researchers, academics, journalists, policy writers, lawyers and politicians in local and state governments. We recognise that none of this could have occurred without the strong sense of community, support and guidance we have received consistently from our network of sex industry peers.

More than professional colleagues, we have become very close friends over the last ten years. Apart from collaborating on this chapter we have shared many hours together - either in front of the computer, at rallies and protests, or in meetings, conferences and workshops.

In this chapter we have deliberately chosen to present our personal quotes without indicating which of us is speaking. Through this ambiguity we

encourage the reader to evaluate the issues without getting bogged down in moral arguments linked to the client's sexual preferences or the sex worker's gender.

Our involvement with "Intimate Encounters"

An early project in which we were both involved was Belinda Mason's groundbreaking photographic exhibition "Intimate Encounters". Since 2001 this widely acclaimed exhibition has traveled throughout Australia and numerous other countries. The exhibition consists of 40 photographs that represent the experiences of sexuality expressed by people with disability. The works seek to challenge the usual stereotypes by creating a new representation of disability, one that is empowering and affirming of them as sexual beings (Intimate Encounters 2008).

By participating in the exhibition, we gained opportunities to extend our networks in the disability sector. As the exhibition travelled and started to gain momentum, so too did the media's interest. This, in turn, increased awareness about the sexuality of people with disability, including their access to sex workers.

To date, 'Intimate Encounters' has been shown in over 30 galleries. However, in some locations, the exhibition was considered too contentious and confronting. For example, it was "deemed inappropriate for display" at the Northern Territory's parliament house by the Speaker of the House (Stateline 2004). In response, the local art community offered the exhibition a free space in the centre of Darwin. The then Chief Minister of the Northern Territories, Clare Martin, opened the exhibition before an audience of 600. An estimated 25 per cent of Darwin's population visited the exhibition (B Mason 2008, personal communication, 15 August).

The majority of visitors to the Intimate Encounters exhibition have given overwhelmingly positive feedback. However, the photographer has advised us that those few visitors who gave strongly negative feedback expressed disgust at the depiction of sex workers 'at work' with people with a disability (B Mason 2008, personal communication 15 August). This demonstrates the continuing discrimination against sex workers and people with disability alike.

Looking back, the year 2000 was a magical time. Sydney hosted the Olympics, Intimate Encounters was being produced and suddenly people from a multitude of workplaces and disciplines began to talk about the issues. An increasing number of sex workers were seeking advice about how to work with clients with disability. At the same time, an increasing number of clients with disability contacted relevant government and non-government organisations, seeking sex workers happy to provide services to them.

This increase in interest led to a meeting of interested parties, hosted by a local sex worker organisation. The main focus of discussion was the establishment of ongoing collaboration to advocate for both the sexual rights of people with disability and the occupational and educational rights of sex workers. A core group was formed to represent the interests of people with disability, sex workers, sexual health educators and disability rights activists. Our first priority was to organise a forum where people with disability and sex workers could meet face to face and, for the first time, candidly share their perspectives in a safe and respectful environment. This was the genesis of 'Touching Base'.

Touching Base: right place, right time

This first forum, held in February 2001, attracted approximately 50 people. Having received a small grant from the Australian Society of Sex Educators, Researchers and Therapists NSW, we secured a fully accessible hotel conference room in a central location in Sydney for the day.

Attendance was strictly limited to sex workers, people with disability and their personal care attendants or regular carer. This allowed for open dialogue without third parties whose presence might compromise participants' ability to speak openly about the barriers they faced. We were mindful that some participants might find these discussions quite emotional, especially if they had not had any previous opportunity to speak about their personal desires, experiences or concerns. Thus we ensured that two competent counsellors, well versed in sexual health and disability issues, were available at all times.

Even in these earliest days Touching Base attracted international interest and support that recognised that we had taken the lead in confronting issues previously placed in the 'too-hard basket'. We were delighted when Dominic Davies, a leading UK disability sexual rights activist accepted our invitation to facilitate this event, as he had recently delivered a paper on sexual facilitation for people with disability in San Francisco (Davies 2000a).

With this forum, we took the opportunity to conduct the first needs analysis to consider the perspectives of sex workers, people with disability, carers (including family members) and personal care attendants. The following seven key areas were identified in forum discussions: laws, consent, privacy, funding, access, training and choice. In addition, a recommendation was made to form a permanent Touching Base committee to address deficits in the areas outlined above.

My group included a man with significant impairments and his mum. It took him nearly 10 minutes to type out his request which was, "All I want is someone to touch me all over my body once a month," punctuated with a cheeky smile! We both knew "all over" specifically included genital stimulation! I was deeply moved when his mother said, "My son has so few opportunities to experience pleasure in the same way as others. Who am I to stand in his way of feeling sexually satisfied?"

At this time New South Wales was the only jurisdiction in the world with a decriminalised legal environment for most of the sex industry. Decriminalisation, in place since 1995, finally permitted open discussion between all stakeholders on these highly personal and sensitive matters, without the threat of criminal sanctions.

Having worked under all types of regulatory regimes, decriminalisation is the only model that comes close to respecting my rights and allows me to speak openly as a sex worker. I have many friends overseas who would love to set up organisations like Touching Base but would be arrested for trying. I know some of them do see clients with disability but these appointments are set up surreptitiously, with no training or

support and with the constant fear of arrest and exposure hanging over both the client and the sex worker.

It is unfortunate that Touching Base has had to spend considerable time and effort advocating against barriers caused by incorrect interpretations of the law, and misinformation about it. In particular, we have had to address policies that misapply the local law pertaining to the “procurement” of sex workers (New South Wales Government 1900). The NSW Government sees no legal barriers and its Department of Ageing, Disability and Home Care has supportive policies in place. However, some non-Governmental disability service providers persistently misinterpret the intention of this law. Their policies forbid staff to assist their clients in any way to access sex workers. For example, we have personally encountered a staff member who refused to make a telephone call to a sex worker on behalf of a client who cannot speak.

Evolving from ‘group’ to ‘association’

Initially there was a bit of resistance from some of the disability service providers we invited to join the committee. We heard on the grapevine that some were suspicious that it was just a blatant act of solicitation on the part of local sex workers. For others the results of the forum spoke for themselves: we were obviously working in the interests of people with disability and sex workers.

By March 2001, Touching Base meetings included individual sex workers and people with a disability, as well as representatives from a local sex worker organisation and a number of large and respected disability service providers. Since that time, monthly meetings have been generously hosted by People with Disability Australia Incorporated (PWD), a national peak disability rights and advocacy organisation. As well as being fully accessible, the meeting venue has telephone conference call facilities which allow participation by those who are unable to physically attend. This has allowed committee members with a disability to fully participate in meetings without incurring additional travel and personal care costs.

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 by everyone we have met through our work with this organisation. We know that for some people this has been the first time they have ever consciously met a sex worker, let alone worked as equal partners on a project with us. By the same token we have been very lucky to work with others of such high caliber and who are so willing to freely share their knowledge and skills with us, not to mention advocating for us to gain access to resources available through their organisations.

Having evolved from an ad hoc group, Touching Base had matured into a incorporated association by 2006. The administrative structures we adopted permits Touching Base the status of a benevolent charitable institution under Australian taxation law.

Principles, aims and intentions of Touching Base

Touching Base operates under principles and aims which were developed in consultation with our members and stakeholders. For example, our Rules of Governance ensure that the positions of President and Vice President are reserved for members who are sex workers and people with disability.

Touching Base Principles

The decriminalisation of sex work in NSW in 1979 recognised sex work as a lawful occupation. The Sex Industry has a wealth of practical knowledge in dealing with a wide range of sexual issues and has the right to be respected and consulted as primary stakeholders in any matters relating to the provision of sexual services.

As the initiators of the Touching Base project, sex workers in NSW are actively pursuing this right.

People with a disability have an intrinsic right to sexual expression. This right enables people to develop relationships, have sex, explore and express their sexuality and achieve intimacy without personal or systemic barriers.

Furthermore, necessary personal and systemic supports must be provided for the expression of this right.

Touching Base Aims

As part of a commitment to supporting such rights, Touching Base NSW aims to:

- Facilitate the links between people with a disability, their support organisations and the Sex Industry
- Encourage information sharing and educational training programs for sex workers, people with a disability and their carers.
- To raise the public and professional awareness of the issues surrounding the access and provision of Sex Industry services for people with a disability (Touching Base 2008a).

Some have criticised Touching Base under the misapprehension that we promote access to sex workers as the *only* option for people with disability to explore or express their sexuality. However, our intention has never been to limit the options available. Rather we seek to ensure that people with disability can enjoy the same freedoms and choices that people without disability have.

Research into the attitudes and needs of disability service providers

The forum identified a deficit in support services' capacity and willingness to respect and facilitate the sexual rights of people with disability, including the right to access the sex industry. As a first step to address these deficits, Touching Base collaborated on a research project with the University of Technology, Sydney (Robinson 2002).

After consultation with the Touching Base Committee, a survey was distributed to a selection of disability service providers and advocacy groups. This survey sought information on:

- Current education and training for service providers about sex and the sexuality of people with disability;
- Current levels of education and training for people with disability about sex and sexuality;
- Service provider attitudes towards people with disability accessing sex work services;
- Instances and circumstances where people with disability have requested access to sex work services; and
- The types of barriers encountered by people with disability requesting access to sex work services.

In total, 169 surveys were sent out with a response rate of 21.3 per cent (n=36). For such a contentious issue, this was seen as a success in itself. A particularly interesting finding was that while most respondents were supportive of people with disability accessing sex work services, this was not reflected in organisational policy. Up to 85 different barriers to access were reported, with most respondents reporting multiple barriers. Family attitudes were given as one of the most prominent barriers. One respondent noted that “these issues cannot be discussed, let alone investigated. Clients of this service are rarely permitted by family members to have relationships of any kind, whether informal or with a sex worker” (Robinson 2002: 26).

This research gave us the evidence we needed to refine the priorities of Touching Base. It also served as an advocacy and awareness-raising tool within the disability sector. For us, it highlighted the value of being involved in research from the very earliest stages. Our early involvement helped ensure that the research was conducted in a sensitive and informed manner. We could also make certain that the questionnaire did not include wording or concepts that discriminated against sex workers.

The survey results supported the anecdotal evidence that had instigated our involvement and re-iterated the forum’s findings. Unfortunately, the results also showed we had a long way to go to address all the research recommendations. These included: increased advocacy, information sharing, resource development, training and the development of a referral list for sex workers who are willing, experienced and/or trained to provide services to clients with a disability.

Participation in the 2002 Sydney Gay and Lesbian Mardi Gras

In a public demonstration of solidarity, sex workers, people with disability and their supporters marched under the Touching Base banner at the 2002 Sydney Gay and Lesbian Mardi Gras for the very first time.

We were overjoyed to see such enthusiastic desire from people with disability to march. In fact there were many more people willing to attend than available carers. So much so that in the end one organisation had to draw straws to decide on who could go. It was very disappointing to hear that only one in five was able to be supported on the night. At least some carers who were afraid of being erroneously identified as ‘gay’ or ‘lesbian’, put their own fears aside, and they came

up with creative ways to disguise their appearance, in order to still be there on the night.

Over half a million spectators viewed the parade. It was amazing to constantly hear the roar of the crowd as we passed by. It was the first time some had ever received recognition or positive affirmation as sexual beings. To receive it from so many people, all at once, made this night unforgettable. They say a picture tells a thousand words: none more so than the photos we took that night. The best of these can be found in the gallery of the Touching Base website.





The Touching Base website

As time went on we received a growing number of requests for information from various stakeholders. It became obvious that service providers and people with disability were having difficulty accessing relevant information. The solution was to collaborate with five UTS students to build a website that was fully accessible to people with mobility, dexterity and vision impairments.

This presented some challenges, as none of us had ever designed a website before. The students were very tolerant of our ignorance and showed a remarkable dedication to achieving the best result possible. They were rewarded with outstanding grades while we received a website that, to date, is regularly utilised both in Australia and internationally. Most importantly, it gives people the opportunity to share their personal stories about accessing the sex industry.

Through both personal experience and my work with Touching Base I realised that the same questions were being asked about the sex industry time and time again. This gave me the impetus to create the 'Frequently Asked Questions' page for the website. I understood it could be a daunting experience trying to access a sex worker if you've never met one before, or if you have formulated your opinions through representations in the media that have been clouded by moral hysteria.

The website was formally launched in early 2004, at a venue generously donated by a local Returned Servicemen's Leagues Club. Preliminary speeches were given by Dr George Taleporos, Rindy, Eva Cox AO and David Cunningham. The website was formally launched by the

Governor of New South Wales, Professor Marie Bashir AO, who provided a very moving presentation of her thoughts about the work of Touching Base. This was followed by a stirring performance by the Australian sex worker performance troupe, *Debby Doesn't Do It For Free* (2009).

Professional Disability Awareness Training

At the 2001 forum, the need for specific sex worker training to meet the needs of clients with disability was universally acknowledged. By November 2001, we had delivered an extensive three-day workshop auspiced by FPA Health (now Family Planning NSW) in Ashfield, Sydney. The workshop covered topics such as: definitions of disability, history of people with disability, values and attitudes, communication, medical aspects, access, occupational health and safety, the role of parents and carers in the lives of people with disability, legal issues and psychological health and safety for workers. The Service Provider research results were released November 2002, further identifying “the immediate necessity for more appropriately trained sex workers in relation to disability awareness.” (Robinson 2002).

Since then Touching Base has gone on to deliver one-day workshops in Wollongong (2005), Sydney (2005), Newcastle (2006), Sydney (2008) and Brisbane (2008). As far as we know, the Professional Disability Awareness Training (PDAT) course is the first training of this kind developed specifically for sex workers anywhere in the world. Participants receive certificates of attendance, issued in both their legal and ‘working’ names to respect the dual identities they may have.

As participants of the first PDAT we personally gained a great deal of knowledge from both the peer-to-peer discussions and the various trainers who volunteered their time to this remarkable workshop. In addition, a critical component of every PDAT is a screening of the multi-award winning Australian documentary *Untold Desires* (Stephens 1994). This moving documentary gives voice to the struggles of people with disability, and portrays the discrimination they face while trying to pursue sexual lifestyle choices. We thoroughly recommend this documentary to anyone with an interest in disability and sexuality.

It has been a great honour to be a part of the development and delivery of PDAT training, especially as it has been so well received by our peers, as demonstrated by the following feedback provided in a post-workshop evaluation: “... presenters were flawless in their respect for sex workers, and clearly the high esteem with which they hold our profession. It was really comfortable and supportive, and a great learning environment” (Touching Base 2008c). Another participant wrote, “There can be a lot of nervousness in seeing a client with a disability in not wanting to do anything ‘wrong’. This great day of training has really increased my confidence and my sense of being able to give clients with disabilities a good service” (Touching Base 2008c).

Vocational training also acts as an advocacy tool, since it gives sex workers greater recognition as professionals. Service providers have told us they have greater confidence in accessing a sex worker for their client if they know the worker has attended a PDAT workshop. The same applies to clients who make their own bookings, as highlighted in the following feedback from a happy client:

Through Touching Base I was able to contact a lady who came to my home. This was the best sexual experience I have ever had but not only was it satisfying physically but also psychologically and intellectually. Without Touching Base this would not have happened and I am very grateful for its existence (Touching Base 2008b).

Service Provider Awareness Training

By 2004, the Touching Base Committee received its' first invitation to run a workshop especially for disability service providers. *Touching Base at Your Place* was held at a disability service provider's premises for 16 participants working in this field.

The positive feedback from the initial workshop led Touching Base to develop a stand-alone, one-day training module called Service Provider Awareness Training (SPAT). After two successful workshops in 2007 and 2008, popular demand has grown sufficiently that SPAT now runs twice a year. SPAT covers a range of topics including: gaining informed consent, duty of care, legal and policy issues, identification of barriers and strategies, solutions and tools to overcome them, including a guide to accessing sexual service establishments. SPAT also provides a unique opportunity for participants to develop new peer-support networks and engage in collaborative problem-solving.

We always strive to employ people with disability and sex workers as presenters, as it gives participants the opportunity to hear personal anecdotes that give depth to the information being provided. As well as providing personal perspectives, these presenters can also answer any questions placed in an anonymous question box throughout the day. For many participants, the workshop is the first place they have ever met a sex worker or spoken about sexual matters with a person with a disability.

As sex workers it's never been hard to impress the participants as, quite frankly, they often arrive with a low opinion of our capacities beyond the bedroom. We often get told how 'normal' we look and how well we present. It's amazing, though, how fast you can bridge the gap of ignorance and fear with a good dose of humour and down-to-earth attitude towards sex and the services we offer. By the end of the day it's wonderful to see how far their attitudes and opinions have shifted.

We have found that an effective way to challenge myths and prejudicial attitudes towards sex workers is to run a group activity where we compare the stereotyping and discrimination faced by people with disability with that faced by sex workers.

It's amazing to see the light turn on in their eyes when they realize that the experiences of members of these marginalised communities are similar on so many levels. The essence of these similarities is that sex workers and people with disability are often considered not to be responsible enough to have agency over their own choices.

Many participants rated the opportunity to hear directly from sex workers and people with disability as the most valuable aspect of the workshop. In addition, every single participant has stated that they would recommend SPAT to others.

The Touching Base sex worker referral list

Prior to the establishment of Touching Base much of the contact between sex workers and their clients with disability in NSW had occurred surreptitiously, with no formal mechanisms existing to connect them. The participants of the first PDAT provided the basis for a referral list of trained workers, which was considered an urgent priority right from the beginning. A small number of commercial sex services premises have been added over time if they are accessible and provide disability friendly services.

Initially maintained by a local sex worker organisation, the referral list has been managed by PWD since 2005, as they have dedicated intake officers who are experienced in facilitating clients' access to a range of supports and services including referrals to sex workers. In 2005, the list was expanded to include sex workers who identified as experienced and/or willing to work in this area. This helped meet an increased demand for sex workers from the disability sector. It was also an acknowledgement that some clients with disability are happy to see a sex worker who will treat them with respect and dignity, regardless of their level of prior experience or training. It also recognised that many sex workers are quite able to adapt their services to the specific needs of a person with disability without 'formal' training.

While the referral list was predominately made up of workers and establishments based in metropolitan Sydney, an increasing number of inquiries were made for appropriate services in other areas of NSW and around Australia. Emails seeking referrals to sex workers have also been received from as far afield as the USA and Dubai. While, unfortunately, sex work is still illegal in those countries, our personal dream is for decriminalisation to occur globally, so that organisations like Touching Base can facilitate similarly open discussions, training and referrals without legal sanctions.

Conference presentations by Touching Base

The development of Touching Base has paralleled an ever-increasing interest in the field of sexuality and disability. This has led to an increase in demand for Touching Base speakers to present at a range of conferences and fora. Of particular note is the increase in requests for sex workers to share their own stories and unique perspectives on working with clients with disability.

The pursuit of social justice often requires members of an affected community to stand up and speak out in order to promote change. This is why, many years ago, we both chose to 'come out' openly as sex workers. Traditionally, sex workers maintain a very low public profile in order to avoid the negative effects of stigma and discrimination. However, these opportunities to present publicly have been of great benefit to us and our peers.

I have found it quite exhilarating to be able to present at conferences. I've seen a ripple-effect: each person goes away from the day with a

new found perspective and respect for the work I do which they share with friends and colleagues.

We have seen how our combined experiences have helped inform the development and direction of Touching Base, and in turn how the achievements of Touching Base have had a profoundly positive impact on our ability to provide professional services to our clients with disability. What we had not anticipated was the degree to which we would become involved with third parties when arranging and providing services to clients with disability.

Working with third parties

Sex work predominantly involves a discrete liaison between the sex worker and their client. If third parties are involved they are usually someone already familiar with the workings of the sex industry, such as the manager or receptionist of a sex industry establishment. With some clients with disability we suddenly find ourselves discussing personal details with a third party who is not actually seeking our services. A different level of professionalism is required when talking with a client's family member or disability service provider. It can be quite awkward for everyone involved when we discuss details such as: the logistics of appointments; our personal description and range of services offered; our fees; our client's desires; and any specific requirements we or the client may have during or after the appointment, such as privacy protocols or transfer requirements.

Service providers (personal care attendants, organisational structures)

When a man living in supported accommodation, spells out on his communication board "Could you please order a pepperoni pizza with extra olives?" his carer or support worker would not think twice about doing so. The fact that the carer may be on a diet, vegetarian or just dislike the taste of olives has no bearing on them being able to swiftly perform their job. If, however, the same man spells out "Could you please ring around and organise a leggy redhead who will come and have sex with me this Friday night?" the response from the same carer may not be so predictable or professional. Instead we have heard story after story of people being reprimanded and refused assistance when the carer's personal values and beliefs influence their professional conduct.

Obviously, clients with significant mobility, dexterity or communication impairments require assistance to make a booking with a sex worker. For some of our clients, arranging an appointment becomes more like a theatre production than a discrete interlude between two consenting adults.

For one of my clients, it took over a year for the appointment to occur. It took the involvement of a sexual health counsellor, his personal carer, the house manager and the manager of a temporary care facility for us to finally meet. After a year of prolonged negotiations to address confidentiality, sexuality counselling and educational needs we had finally reached the point where everyone felt comfortable that informed consent was given. Even after all that, four of us were still forced to wait with him in a car park for over half an hour for someone else to arrive with the key to the room. This was a long and uncomfortable 30

minutes for all of us as due to complicated confidentiality boundaries previously agreed upon; none of us were able to talk about what we were waiting for. As if this wasn't bad enough, the room was unprepared, had no spare linen nor towels, and we were interrupted when the cleaners – oblivious to what had been previously arranged – let themselves in with their own key.

Sometimes we hear through a 'fourth party', who is often a friend and informal advocate that a client definitely wants an appointment but that their immediate carer has ignored their request. It has never been the sex worker's role to initiate appointments. We do not feel comfortable doing this but in some cases we know that if we do not take the initiative nothing will ever happen for this person, regardless of his clearly expressed desires and our willingness to provide services. Without the assistance of friends and advocates, the client can be left in a void, rendered powerless by a form of passive aggression that ignores their right to self-determination. In these situations, the term 'support agency' becomes oxymoronic. The agency is clearly failing in their role to facilitate and support the client's choices and access to services.

One client of mine has faced enormous resistance from the manager of his group home when trying to see me. After months of careful organisation his appointed financial managers had released his money, after we had agreed upon the time and the place, the services and the price. All that was left was to ring a cab and get him to my place. Believe it or not, the 'support' staff blankly refused to write down my address to give to the cab driver just because they knew he was to be driven to a sex worker's home. The appointment had to be delayed for another month while the advocate found a cab driver who she could contact directly on the client's behalf. A few months later, another appointment was made for 3 pm. Using the same cab driver as before; it was arranged for him to pick the client up at 2 pm. The designated time came and went without my client's arrival but luckily I had the phone number of the cab driver. I discovered the cabbie had been turned away at 2 pm with support staff saying to come back at 3 pm because the client wasn't ready. The house manager has made it clear that her actions are based on moral objections alone.

Family (parents and siblings)

Charlie is usually involved with arranging appointments with me. His mum picks me up from the train station and drives me back to their family home: unusual enough in itself! Recently though, she rang asking if I was available for a 'surprise' visit as a special present for Charlie. On the day, she was clearly excited at springing this surprise on her son.... but you should have seen Charlie's face when he realized that it wasn't Auntie Gloria walking through his door, as his parents had pretended! He was delighted! As we all stood in his bedroom laughing it occurred to me how special this moment was, for all of us in our own way. For me, it really validated that the work I'm

doing is seen as having real value. While most parents don't often know the details of their child's sexual lives, here were Charlie's parents celebrating the arrival of a sex worker into their son's bedroom. I only wish that those people who express disgust at what I do could download this moment from my mind, to experience first hand the pure joy we experienced together. Charlie may never be able to hit a home run but with his parent's blessing he could still get to third base!

Family disapproval was a barrier commonly cited by service providers considering helping a person with disability to access sex workers (Robinson 2002). Fortunately, we have both met some exceptional parents and siblings who exhibit great strength and determination to ensure that their family member is able to express himself sexually.

I have a client whose sexual exploration became an international family affair. One brother contacted me to provide services to his sibling. He brought his brother to my house and paid me, returning in an hour to pick him up and take him home. A few sessions later I discovered that a third brother sends the funds from overseas! How wonderful it is to know that these brothers care and support each other in this manner. For a while there it was their little secret from their parents ... until he blurted it out one day in excitement! I still see him to this day.

We have also met parents who, while they feel unable to directly assist their own adult children to access sex workers, are quite prepared to swap roles with other parents in similar situations. They have told us that although they do not want to be intimately involved in their own child's sex life, they are not prepared to just sit by and ignore his sexual needs. Some have even been willing to share their lifting and transfer skills with sex workers at Touching Base workshops! The trust shown to us by some our clients' families demonstrate that we can provide a safe and caring environment comparable to that of other professions.

Families and support staff often express fears that a client, who may be vulnerable due to the nature of his disability, may be taken advantage of physically or financially. In our experience the sex workers who choose to work with clients with disability do so with the greatest integrity. In the seven years, Touching Base has never received any complaints of such abuses about workers they have referred.

The mum of one of my clients even direct debits my fees directly into my bank account each week. She has no way of checking if I actually turn up each week or that I will provide the services that she has paid for, as her son has difficulties with his short term memory. On the times when he requests 'extra' services she never questions me and is happy to pay the extra costs, but does not necessarily want to know the details of what these 'extras' involve. She respects my professionalism and trusts that I would never try to rip her off.

Financial constraints have made some families fearful of unleashing desires for sexual activities that are unaffordable in the long term.

One of my clients has only ever experienced a sexual massage with hand relief. Even though he has expressed a desire to experience oral sex, his parents had to say no because they just couldn't afford the ongoing extra cost that could arise if he liked it and wanted it again. They seemed to think that it would be easier for him to never experience this, rather than disappointing him by denying him more in the future.

New directions

Although there is extensive anecdotal evidence of sex workers providing services to clients with disability, both in Australia and overseas, very little research to date has this topic as its primary focus. Recognising the value of empirical evidence when advocating for change, we have chosen to pursue two research projects at the University of Sydney, designed to be complimentary.

Rachel is conducting a quantitative survey which aims to gauge the extent to which NSW sex workers provide services to clients with disability. She will be investigating: where such service provision occurs, the frequency of such services, the type and range of services provided, if clients arrange their appointments themselves and/or need the assistance of a third party, as well as exploring any barriers faced by sex workers providing these services.

Saul's research is a qualitative study that aims to investigate and document the use of sex worker services by men and women with cerebral palsy, living in supported accommodation in NSW. He will explore participants' reasons for seeing sex workers, any barriers they may have experienced, and strategies used to overcome barriers. Changes in their sense of self, enjoyment of life or relationships with others will also be examined.

We hope that the results of our research will be used to further promote the sexual and human rights of both sex workers and their clients with disability, both in Australia and elsewhere around the world.

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CHAPTER 10

The Disabling Effects of a Sexed System: An Exploration of Intersexuality, Transsexuality and Sexual Citizenship

Zowie Davy

Accessible Summary

In this chapter, I look at how doctors decide on what sex you are when you are born. The birth certificate is very important for somebody's sexual and gender identity. I did some research and found that some people are born with uncertain genitals and that these people do not fit easily into being a male or a female. Usually doctors operate on the child's body to make it look more like a male or a female body.

For some people even if the body looks male or female, sometimes this does not feel right to them. To show this, this chapter also talks about Gregory who was born a girl but has decided to live his life as a man. Gregory changed from being a girl, to being a lesbian, to finally becoming a man. I also found out that:

- When Gregory was young, people did not think he would get married because he was disabled.
- Some people like teachers and doctors cannot understand that people with impairments want a sex life.
- Some doctors think that bodies should fit into male and female sexes.
- The male and female sex is not enough for the different types of bodies born.
- The law treats people with different types of sexual bodies differently to those with non-disabled bodies.

Introduction

I use the concept "transsexual" throughout this chapter to indicate a specific trans identity, which connotes a sense of transition from one sex to the other. Many transsexual people do not necessarily identify with this concept. Some may identify as woman, man, transgender, trans and so on, as this indicates that their subject positions are about gender rather than sexuality. However, some transpeople do not like the term transgender as it is commonly understood as an umbrella term that incorporates many identities who may not necessarily transition socially or legally I also use the term intersexual. Intersexuals are understood medically as having sexually impaired bodies. Transsexual, intersexual and disabled bodies occasionally cross paths in disability studies as illustrations of the medical model's negativity towards "unsound" body morphologies (Shildrick 2002). Medical discourse about bodies is based on heteronormative, normatively gendered, non-impaired bodies as nature's ideal (Price and Shildrick 1998), leaving transsexual intersexual and impaired bodies as metaphors for moral and physical degeneracy. The latter group of bodies have difficulty entering into normative citizenship rights on many levels; however, arguably none more so than within sexual citizenship. I use the term sexual citizenship to include the responsibilities and rights of sexed bodies and sexual acts. Quite simply, to

have a sex ascribed at birth will determine your sex in law and your sexuality in any relationships that are legislated upon, such as marriage and civil partnerships. Judith Butler's (1990) concept "heterosexual matrix" illustrates the universal assumption that the sexed body is prediscursive in opposition to gender which is culturally constructed. She suggests that sex too is constructed through the medicolegal system. In this chapter, I will illustrate how the sexed body is constructed differently in relation to normative, intersexual and transsexual bodies in the UK. I will draw on the phenomenological experiences of Gregory, a transman who is disabled and identifies as queer (queer, according to him signifies that he is moving beyond binary notions of sexuality). Gregory's complex story reveals the ways in which he negotiates his sexual citizenship through various embodied identities. Gregory's negotiations are structured by the (dis)abling effects of medicine, law and family, through the birth certificate, which has much power in granting him social legitimacy.

In this chapter I adopt an intersectional framework of disabled, transsexual and sexual identities to offer nuanced explanations of how Gregory employs his autonomy and agency in securing a coherent identity in the face of UK legislation, even if psychosocially his intersected identities are dynamic and adaptive. Gregory's story is not to be read as one brought on solely by his impairments, gender dysphoria—a psychiatric concept, which asserts that people feel a profound discomfort with their ascribed gender and wish to appropriate the opposite gender—and his queerness, but as an intra and intersubjective negotiation with the social world he encounters and embodies. Moreover, it is important to see how the fluid identities Gregory identifies with, temporally, are inscribed by gender and sexual discourse, but can also be revised, contested and occasionally rendered obsolete (J Butler 1993). This chapter calls for a fresh look at the birth certificate, what I consider a fundamental aspect of sexual citizenship. I start by exploring the context of citizenship in relation to intersexual and transsexual bodies. I move on to interpret Gregory's narrative through a phenomenological epistemology. This I hope will contribute to the debate on disability, embodiment and sexual citizenship.

My Epistemological Approach

Phenomenological epistemology works on the understanding that Gregory's story will be interpreted by me through the way he experiences and senses his body, and how he acts and thinks through his corporeal self.

Phenomenology helps us understand the body/self as an imbricated whole, which rests upon, amongst other aspects, corporeal capacities and intentionality. According to Merleau-Pontian phenomenology (Merleau-Ponty 2002[1962]), intentionality is defined as: a consciousness about something in relation to the lived body and the world in which it dwells. Perhaps it is the focus upon bodily capacities, which influence many disability scholars to turn away from phenomenology as a tool of analysis. However, and with good reason, these disability scholars seem to be equating bodily capacities with those of a universalised normative (masculine) standard, which is not necessarily the case in phenomenological interpretations. For instance, feminists such as Iris Marion Young (1990) and transgender theorists like Henry Rubin (2003) have used a phenomenological approach to decentralise

the universalised non-disabled body (Price and Shildrick 1998) and draw attention to gender relations and sexual difference, illustrating that it can be useful for understanding bodies other than what is assumed.

Corporeal Citizenship

Control over bodies is operative from the moment a doctor decides on the 'sex' of the infant. The sexed body is constituted in a number of social fields, law and medicine being the most influential, in what I term the "medicolegal" alliance following Judith Butler's (1990) definition. Moreover, there are responsibilities applicable to particular sexes, which commence in early childhood. I am not the first to suggest this. Radical feminists made determined attempts to connect sexed bodies to the unfair social position(s) of women under patriarchy (Raymond 1980). Whilst radical feminists have been helpful in drawing attention to the connection between bodily difference and social hierarchies, they have less to say about how bodies are implicated in citizenship debates (Bacchi and Beasley 2002). Moreover, intersexual and transgender embodiment, which this chapter will go on to consider, does not sit well with a radical feminist framework (Jeffreys 2005, Raymond 1980).

The privileged part played by corporeal boundaries is intrinsic to the birth certificate and in figuring the sexed body politic. The surveillance by doctors of bodily aesthetics has a close relationship to state regulation and which habitually creates a bi-sexed social order. I use the concept "bodily aesthetics" to refer to the appearance of the body that sustains judgements about sexed identities and their worth. Judgments about bodily aesthetics in relation to the birth certificate in the UK, and much of the western world, provides a declaration of sexed bodies. A birth certificate gives details of being registered in the official register of births. In England and Wales, registering a birth has been a legal requirement since 1st July 1837. Foucault (1998 [1976]) argues that "biopolitics" emerged during the nineteenth century as a result of surveying births, death, health and attempts to control the sexing of the body. This also had other implications because social scientists started including the body's "normal" capacities, gestures and behaviours in their analyses (Fausto-Sterling 2000). Judgments by some social scientists about bodies and their subsequent worth overlooked the possibilities of bodies being neither essential nor that their seemingly fixed elements, such as chromosomes were produced through gendered social discourses (Fausto-Sterling 2000). Contemporarily, transsexualism, intersexuality and sex change surgery stand as instances of fluidity, but nevertheless, are restrained by numerous controlling mechanisms that maintain citizenship hierarchies based on sexed bodies and sexuality.

These fluid sexed positions are constituted within the medicolegal system, which places limits on bodies and dictates the legitimacy of these bodies in relation to citizenship and law. The judging of non-normative bodies as deserving citizenship rights is made acutely apparent with transsexuals and intersexuals. I do not wish to suggest that those with normative bodies do not have the same controlling mechanisms, but that any attempt to understand sexual citizenship requires knowing how transsexual, intersexual and disabled bodies enter citizenship discourses differently.

Intersexuality and the Birth Record

Intersexuality in its many forms—Turner’s Syndrome, Klinefelter’s Syndrome and Androgen Insensitivity Syndrome to name a few—is defined as congenital aberrations in sexological literature. Known historically as “(pseudo) hermaphrodites,” intersexuals are initially sexless, in a socio-legal sense, unlike the majority of infants who are assigned as either male or female and registered as so on the birth certificate. John Money, amongst others, in the 1950s and the paediatric endocrine group at John Hopkins University started, with consent from families, to assign infants born with ambiguous genitals an “optimal gender” (Money, Hampson and Hampson 1955). The “optimal gender” policy is one of John Money’s best-known theories. Assignment decisions by doctors and families were based on the expected optimal outcome in terms of psychosexual and reproductive functioning and including a stable gender identity. Money et al. (1955) proposed that newborns are born psychosexually neutral. If the newborn is genitally and thus, “sexually ambiguous,” this need not be a problem, for when the “optimal gender” assignment is decided, surgical procedures performed, and gendered rearing commences, the infant will automatically assume the gender of assignment as well as heterosexuality (Money 1975). In his later theorising, Money (1975) argued that gender becomes fixed in the first three years of a child’s life through the gender rearing and socialisation, resulting in an appropriate gender identity, gender role and gender presentations of either masculinity or femininity.

Medical models incorporate only two sexes. Hester (2004), writing on the sociology of intersexuality, suggests that the way a doctor determines a sex of an infant is by regarding the aesthetic arrangement of their genitals. If the genitals are ambiguous, the doctor may require additional information in order to extract the ‘authentic’ sex of an infant. Additional information could consist of phenotype, chromosomal make-up, and gonadal tissue, which would be considered along with the morphology of the genitals. However, Dreger argues:

in the late twentieth century [doctors] do not search deep into an intersexual’s body in the hope of finding material marker of an ontologically ‘true’ sex. Instead, doctors today see their approach as pragmatic and primarily attentive to a psychosocial gender identity theory rather than a bio-medical-materialist philosophy of sex identity (Dreger 1998: 181).

So, the data deemed necessary by the paediatric team would be considered against the back-drop of Money et al’s psychosocial developmental “optimal gender” policy (Money *et al.* 1955). The experts’ decisions would result in the conjecturally optimal gender that the child be socialised into.

Chau and Herring (2002) argue that the established approach was that the penis of less than two centimetres should be removed, as should a clitoris greater than one centimetre. It was felt that boys with such short penises would suffer from low self-esteem and that girls with a large clitoris would feel unfeminine. There were in stances where babies appeared otherwise “normal” except for a “micropenis of clitorine dimensions” (Money 1975: 65). This was regarded as an anomaly and “rectified” often by surgically

creating a neovagina and assigning the child as female. If the child was left as male it was assumed that the small penis would negatively affect his life chances as male. The assignment of the child as female would save the “individual feel[ing] like a freak” (Money 1975: 66). Moreover, doctors in the US and UK have been accused of creating ‘female’ genitals out of ‘male’ ones and pressuring families into rearing the child in a “female role” based on the (unfounded) notion that the aesthetic dimension of genitals is the most important factor to future aspects of psychological wellbeing (Kipnis and Diamond no date). Sex reassignment is more likely based on the notion that it is technologically easier to construct a neovagina than it is to create a neophallus (Intersex Society of North America 2004). However, there are now some Eastern European doctors who believe that functionality and sexual pleasure should be the surgeon’s objective (Krstic, Smoljanic, Vukanic, Varinac and Janjic 2000). Nonetheless, the binary sex system is prioritised over these objectives.

Some medical intervention is often required because the prognosis of these conditions implicate that there will be heart, kidney and thyroid problems. The most contentious of the medical interventions critiqued by intersexual activists and academics is the assumption that the often ambiguous genitals require surgical intervention (Fausto-Sterling 2000, Grabham 2007). As intersexual activist Cheryl Chase says:

I was less willing to think of intersexuality as a pathology or disability, more interested in challenging it medicalisation entirely, and more interested still in politicizing [...] the hetero-normative assumptions underlying the violence directed at our bodies (Chase 1998: 199).

Doctors who wish to modify genitals in line with a binary sex system (Money 1975, Money *et al.* 1955), are often seen by activists to be basing their science on an ideology that restricts intersexual citizenship. Hester (2004) suggests that the objectivity of science is underscored with a hierarchy of subjective values, which are premised upon the location and history of the discipline. The authenticity of sex is ordered by literally cutting away the ambiguity and in many cases denying it was ever there (Chase 1998). Thus, doctors are seen to be forcing “ambiguously” sexed bodies into a system unfit for human diversity.

Activists are suggesting that people should be able to consent to medical intervention themselves and because much of the surgical procedures are performed during childhood, doctors are disregarding intersexuals’ human rights (Hester 2004). Furthermore, activists argue that the reason behind the surgeries performed is unnecessary and based on arbitrary, aesthetic reasons.

Implicated in the decisions to intervene alongside doctors are family members both before and after birth. The decisions inevitably affect the fetus’/infants’ corporeality. As Emily Grabham (2007) suggests the decision for or against abortion or surgery is equally significant for intersexuals’ embodiment. She argues that intersexual children are born into a web of relationships that have “the potential literally to result in physical incisions, the removal of tissue, and the administration of hormones” (2007: 39). These

decisions will ultimately affect the position of their sexual citizenship, by providing a normalised body for the birth certificate.

Transsexual's and Intersexual's Ambivalent Relationship to Law

Intersexuality has an interesting medicolegal relationship with transsexuality. Medical discourse constitutes the intersexual person as a casualty of nature gone wrong. Transsexuality, however, is seen as a psychological disorder, where development into an "original" sex/gender within a binary system is thwarted (Benjamin 1966, Money and Ehrhardt 1972). In all the sexological perspectives concerning transsexuality, except maybe those that are based in psychoanalysis (Stoller 1975) and the reparative practices (Zucker and Bradley 1995), the anomalies of embodiment should/could be rectified with surgical procedures (Pauly 1981). The way in which intersexuals and transsexuals are marked differently in the medicolegal context is through the discursive gymnastics employed by the doctors and judges when viewing the sex/gender system (Hird 2000), where the same type of surgeries are seen as essentially different in *intention and deployment*. Historically in the UK this had huge implications for transsexuals, because legal recognition was not granted to them until 2004 and they were not able to change their birth certificate indicating their (new) sex.

Beneath any understanding of sexual citizenship lies the need to explore a most fundamental aspect of citizenship, the sexed birth certificate. Biomedical and psychiatric researchers are excellent at disseminating sound bites of their research in popular cultural mediums, such as newspapers, television and radio, which helps the hegemonies of medicine maintain its convincing authority over sexed bodies. In a brief search of newspaper articles on-line about sexed differences, many articles were proclaiming that there are genetic and brain differences between men and women (for instance, see Guardian online 2003). Some went so far as to claim that transwomen's and transmen's brains were probably "hardwired" in a similar way to women and men respectively. However, there were no articles talking about the incidence of intersexuals. Biologist Fausto-Sterling (2000: 53-54) estimates there to be 1.7 per cent of all births to have varying degree of intersexual development. In no news article that I found did they suggest which type of brain someone with intersexual development might have. Is this because this argument would undermine the commonsense view that there are only two sexes (Kessler and McKenna 1978)? Is it because those who do not fit the system undermine much research surrounding sexual difference? To truly understand these power relations we need to begin with the local (private) and explore patterns of practice and discourses and their interrelations with bodies. Then we will see how discourses become inert and seemingly fixed bodies of knowledge (Foucault 1998 [1976]). I suggest it is the birth certificate, which acts as an inert and seemingly fixed aspect of knowledge that becomes oppressive in relation to sexual citizenship rights and especially for those who seem to have non-normative bodies. For those with normative bodies there is often no need to look into such a fundamental, almost out of sight, piece of social ordering.

One of the main critiques of medicine in disability studies, and to some degree in the postmodern and queer transgender literature, is medicine's appraisal of the fully functioning body as the standard from which all other

bodies are judged. Medical hegemonies over sexed bodies are apparent in the ways that they authorise representations of normatively sexed corporeality and normative experiences of (hetero) sexuality. Michael Oliver (1990) considers the medicalisation of bodies, a mechanics of social control and ideological coercion. Some have commented that this leads to the development of the personal tragedy theories of disability and that this filters down and influences society as a whole (C Barnes, Mercer and Shakespeare 1999). I suggest that it is the sexological focus on idealised bodies and the “unthinkability” of other bodies, such as intersexuals, which lays claims to ontological sexed identity and by implication sexual citizenship.

Scholars and political activists often consider medical knowledge surrounding bodily aesthetics, but rarely look at the implications of a birth certificate, which sustains family, marriage and sexuality. Of course many aspects of contention can be seen in the New Social Movements’ political praxes, set up to counter medical hegemonies surrounding intersexual, transsexual and disabled bodies; however, there is no debate in disability studies about the birth certificate. There are some intersex activists who have taken up the fight to include a birth sex that is neither male nor female. However, the birth certificate continues to be the birth certificate continues to be an ontological claim, which organises many aspects of citizenship and civil life (Whittle 2002). The decision of which sex should be placed on the birth certificate transmits many social, medical and legal significations. In law the birth certificate affects areas where men and women are distinguished. For example, in some sexual offences, marking who can marry, deciding which sport someone can compete in and so on (Chau and Herring 2002). The bodily sex of the infant, initially pursued by doctors through the “art of perception” (Hick 1999) is taken in most instances as both a routine medical and legal truth. As Butler (1993) asserts experts lay claim to ontology and distribute ontological effects, which is an instrument of power. Ontological claims also affect recognition and exclusion, which, Butler suggests, produces domains of “unthinkability.” From this perspective what is excluded from medicolegal ontology is intersexual embodiment. Legal theorist Andrew Sharpe (1998) suggests that in a legal context, biological determinism is a prerequisite for having a legally sexed body. Biological determinism is however, based less on internal chromosomes or gonadal tissues than on bodily aesthetics and the presence or absence of a penis.

In a UK Home Office publication in 2000 (Home Office 2000) it stated:

The law provides for an entry in a birth register to be corrected at any time if it can be shown that an error has been made. This includes the circumstances where a newborn baby was not in fact of the sex recorded in the register.

The publication continued: “If the sex of the child is not evident at birth, parents are advised to delay the registration until medical investigations have been completed to determine sex” (Home Office 2000: 6). Although there is some recognition of the grey areas of bodily aesthetics for intersexual people, there is only partial acceptance in law. UK law, as it stands in 2009, is willing to wait until doctors have decided on an “optimal gender” (boy/girl) for those

who do not 'naturally' fit the system, but they cannot contradict the binary sex of the birth certificate.

It was reported in *The Independent* newspaper (Finn 1998) that a child in the UK, who had ambiguous genitals, and who was not expected to live, was assigned as male, because "he" had XY chromosomes. The child survived and when the "boy" was one year old doctors operated on "him" and surgically created a "female" body. They thought that she would be able to live her life better as a female. However, after the surgery and change of name to Joella, she was unable to have her birth certificate changed to female. In this particular case her modified body did not adequately indicate her sex. The child was positioned legally as transsexual, who at this time in the UK had no legal recourse to change birth certificates. In 1970, legal sex was determined by a ruling from Judge Ormrod. His ruling stated that at birth, chromosomes and bodily aesthetics were the deciding factors in the "true sex" of a person. Ironically it was the case of a transsexual April Ashley that set this precedent of what "true sex" was. April Ashley and Arthur Corbett wanted an annulment of their marriage. The UK, at that time, did not recognise the mutual consent agreement between the two parties as a reason enough to grant annulment. Judge Ormrod ruled, because of this, the case's primary issue had to be the actual validity of the marriage in the first place. April Ashley was known to be transsexual. The annulment then was dependent on the "true sex" of April Ashley, because if, through a medical test, she was determined to be male, then the marriage would be void as two males cannot get married. Determining the "true sex" was based on four factors. (1) Chromosomal factors. (2) Gonadal tissue (i.e. the presence or absence of testes or ovaries). (3) Genitals, which includes internal sexually dimorphic organs. (4) Psychological factors. The plaintiff had XY chromosomes, had male gonadal tissue and genitals prior to sex reassignment surgery and therefore, was judged to be of male sex. Psychologically she was conceptualised as transsexual. Following an eight year court battle, a ruling by the Office of National Statistics stated that Joella, the ambiguously sexed child, could have her birth certificate changed to female (Finn 1998). The implication of this decision meant that chromosomal tests were no longer regarded as definitive in determining sex. Christine Burns from the UK transsexual advocacy group Press for Change said:

In law, there is no difference between Joella and a transsexual woman and in practice the only actual difference is that gender reassignment surgery was inflicted upon her by others, whereas transsexual people are in the position of trying to get surgery. She has XY chromosomes, just like transsexual women and is sufficient to invalidate her marriage under the 'test' devised by Justice Ormrod (Press for Change 1998).

At that time in the UK intersexuals and transsexuals were considered differently, one an *authentic* sex who was created by a surgeon and one an *inauthentic* simulacra created by a surgeon regardless of other biological aspects. The inauthentic transsexual was still defined in terms of the sex ascribed at birth and as someone who had psychosocial gender problems (gender dysphoria) in opposition to intersexuals who had physiological

(biological) problems. This division can be seen, not as a force of nature, but a privileging and excluding of certain corporeal and psychological relationships. By giving significance to purely psychological factors without any definitive test to confirm them, Chau and Herring (2002: 349) argue this may lead to intersexuals considering “themselves as neither male nor female, but intersexual (or some other designation).” This would create a legal problem that would undermine what Gayle Rubin (1997 [1975]) in another context calls the last bastion of heterosexual kinship systems, marriage and family. Marriage and family continues to have colossal relevance for the political economy of sexual systems and sexual citizenship.

Nonetheless, it was not until the implementation of the Gender Recognition Act 2004 (GRA) that legal authenticity was granted to transsexuals, through the diagnosis of Gender Dysphoria, alongside the will to surgically alter (sexual) bodily aesthetics. Legal authenticity for transsexuals is premised upon medical experts’ ability to determine whether someone is Gender Dysphoric, and it is this connection that assures medicine’s ongoing centrality in the construction of official transsexual identities and sexual citizenship. I now turn to Gregory’s narrative of sexual citizenship in the hope of illustrating some of the capricious aspects of the birth certificate and medicolegally sexed subjects in the UK.

Shifting Identities

Gregory at the time of the interview was 40 years old and lived in a small city. Gregory was profoundly deaf; he had had a crushed windpipe at birth, which subsequently caused him difficulty in breathing and speaking. During his childhood and throughout his adulthood he had been in hospital for numerous operations and observations resulting from his impairments. For the sake of his anonymity I will not give more details of his medical conditions so that I may avoid people identifying him. Gregory started the process of gender transformation from ‘female’ to male in his early thirties. At the time of the interview, he identified as a queer transsexual man. However, as I will go on to illustrate his temporal identities of intersexual, woman, lesbian, transsexual man and now queer transsexual man were regulated primarily from his initial birth registration as female.

In the interview, Gregory focused very little on his impairments as aspects of his identity. The most significant aspect was his precarious gender identity and how he fit with the sexed system. Gregory suggested that he had always felt like a male and suggested that because of his stay in hospital during infancy and early childhood he did not have the same kind of socialisation into the sexed system and female role. Gregory said:

When I was 3 years old I became aware people were using female gender pronouns and I couldn’t understand why, of course because I was in hospital, I did not have the same social experience as everyone else. [...] when I became aware that I had a girl’s name I wondered why, and I was wearing dresses, when obviously I was a boy. So I asked why and they thought I was retarded because of asking [...] So I was treated as if I was stupid because in their view I didn’t understand that I was a girl. Because I had a disability; I was a bit simple, I didn’t understand.

His medicolegal sexed identity had little relevance and he was left in a state of confusion. As Gregory grew older his understanding of his sexed identity was made more acute. During some incidents at school where Gregory attempted to use the toilets assigned for males his mum was informed:

I was called into the headmaster's office to be punished. I said "what for." "Well for using the boys' toilets", I said "well of course." He said "you're a girl" and I said "no I'm not" and I was really insistent and then this problem was reported to my mum. Then my mum started drilling in to me that I was a girl, which she said "well I wanted a girl so that's what you'll be and that's it".

Other incidents at school, where socialisation plays a huge part in the sexed economy, Gregory's role in family life, was seen by teachers as different to that of others who do not have impairments:

In the mainstream school I was put at the back and ignored, really. Then I was put in a special school, where they were nice but they thought it was a waste of time teaching disabled children, really, and I am quoting the headmaster here: the boys all get married and the girls will stay at home with their mothers.

As a female disabled person, Gregory was not seen as ever being able to have a normative private family life or sexual life. What was regarded as typical familial trajectories for non-disabled females was not contemplated by the headmaster for Gregory. Gregory eventually tried to fit in as a girl and later when he went to university he 'came out' as lesbian. Gregory said:

Well my attempt to become female went right up to and continued [tape unclear], but I felt hollow, I was just going through the motions and I thought I wasn't human; I was really living like a robot. When I started university in 1996, I came out as lesbian even though I didn't think about myself as one. Anyway I did feel better temporarily, because I was attracted to women. I thought this in time will solve it, because I am attracted to women.

The sexed identity positions that were available to Gregory, at this time, were restricted by the discourses surrounding the binary sex system, man/woman, heterosexual/homosexual and so on. As Gregory's gender and sexuality pathways had 'normalised' into a tentative female identity, his sexual object choice left only one sexual identity open to him, that of lesbian, even though it was not a comfortable fit. A few years later Gregory had a *eureka* moment whilst reading *The Well of Loneliness* (Hall 1973 [1928]) at which point his identity shifted to that of transman. Gregory identified with the main character Stephen, who he saw as just like him. Gregory however, did seem to have a problematic entrance into the transsexual narrative. He thought he must suppress these feelings so as not to be seen as 'mentally ill.' The wish to change one's gender is regarded as a mental problem in the West as can be seen writ large in the DSM IV (American Psychiatric Association 1994).

The fluidity of Gregory's journey to become a man is often regarded as something people will not understand. The appeasement of society is deemed more important by doctors as I illustrated in relation to intersexuals above. The 'common sense' view that there are only two sexes is directly supported by the medicolegal apparatus. Similar appeasements were expected of Gregory in relation to his transsexuality. This was illustrated by Gregory's psychiatrist who advised him to hide his transgender history.

When the psychiatrist told me to concoct a new life story for my acquired identity (before I was granted hormones), I refused, I informed him that I was not prepared to mislead people – why should they trust me if I did? But I also made it plain that I am who I am now, and that instead of lying, I would always tell the truth, but I put it into context. I also pointed out to him that a false life story had no real advantages.

Gregory was unable to have gender reassignment surgery. The psychiatrist's suggestion to hide his transsexual past was aimed at Gregory's social encounters. Nothing was mentioned about how he should/would approach more intimate relationships. Could this omission be read the same as the headmaster's assumption about Gregory's impaired body, and that because he did not have a normative body he would not want to have sexual or other intimate relationships, or that other's would not find him sexually attractive? Nonetheless, Gregory does have some reservations himself and about his non-normatively sex body, he said:

It is impossible for me to feel confident about approaching potential partners when I don't know if they can accept and relate to me as a man. I also stress about when and how to tell them that I'm trans, especially because I haven't had the surgery. Not everyone can make that quantum leap. People often have rigid ideas about what 'men' and 'women' are, and they tend to be fairly crude, especially at the biological level.

Gregory's Intersexual/transsexual Story

From his birth Gregory has had a precarious relationship with the birth record. He was implicated in medicolegal social ordering from early infancy when doctors could not decide on Gregory's 'true' sex.

I did not know [this] until well into my adult life. Although I was born with absolutely 'normal' female genitalia, for some reason that's never become clear, the hospital were convinced that I was male even in infancy, and took all manner of samples to double-check my chromosomes, and found nothing 'abnormal'. You'd think that would be that, but it appears that the hospital told my parents that I was probably really male. In my twenties, I discovered (by accident) that I'd been diagnosed with Turner syndrome. [...] For me to have Turner syndrome, I'd have to have been born without internal female reproductive mechanism, and yet mine was all there – as my horrible

gynaecological problems should have told the idiot GP who let the diagnosis slip. I challenged the diagnosis and had to have a lot of tests, which clearly established that I do not have Turner syndrome (Gregory).

After medical tests to 'find' his 'true' sex Gregory was issued a birth certificate with 'female' stated on it. What the quotation above implies is that initially he had an uneasy entry into the sexed system. These unsettled moments in infancy continued to have reverberations later in life. Hidden by doctors for over twenty years Gregory's uncertain sex, he suggests, may have been a positive aspect in his later diagnosis of gender dysphoria. This is only speculative, however, according to Gregory his entry into transsexual medicalisation was an easy process, unlike his personal entry into the transsexual narrative. According to Gregory, he wrote a 'brutally honest' condensed autobiography that included his intersexual ambiguity, which was reviewed by the Gender Review Panel at the Gender Identity Clinic he attended. Gregory said his honesty aided in his diagnosis of gender dysphoria and his subsequent medical treatment for transsexualism.

The connection between intersexual embodiment and transsexual embodiment has historically had a close relationship in medicine (Diamond 2000). In law however, as I argued above, the relationship was divided somewhat differently and premised on a prioritising of certain corporeal relationships to medicalised 'true' sex for intersexuals over the deprioritising of the psychological for transsexuals. In part the disorderly bodies of intersexuals are warranted inclusion into the bi-sexed system insofar as they could change their birth certificate if it was understood that there had been a mistake in identifying their 'true' sex. However, this so called choice was restricted to 'male' or 'female.'

With the introduction of the Gender Recognition Act 2004 the birth certificate has taken on new meanings. Within the Act it specifies no directives to change body characteristics or the need to ingest hormones. The diagnosis of gender dysphoria is sufficient to apply for gender recognition. This means that people can be male for (nearly) all legal intentions and have bodily characteristics usually associated with women, such as vaginas and breasts. Gregory was unable to have any surgeries due to his impairments. The risk to him of such operations and anaesthetic would have likely killed him. Gregory said:

What I did to prove my intentions to have it [surgery...], I sent the letters from the surgeons showing that I had been approved for surgery and then had it [surgery] withdrawn for health reasons.

In a legal sense Gregory pursued a transsexual path which he needed to take in order to gain his new birth certificate. Nonetheless, following my question:

Zowie: How has the law affected you?

Gregory: In some senses it is not that important but in real terms it has helped me because I know now that if I do find a partner, I can marry them, and all the laws that apply to men apply to me. It means if I go into hospital now I wouldn't be put on a woman's ward. If anybody

does get threatened by my gender or use discrimination I have a lot more guards against it. And it makes me feel good. The first thing I thought when the law was first passed was, at last I am a real person, and I exist. When I got my birth certificate at the age of 39, I exist; it is the first time [I exist]. Before, I felt like a part person in the eyes of the law but now I feel three dimensional.

Gregory's body continues to cause him a great deal of discomfort because it is not inline with how he sees his identity. However, the legal framework incorporates those who are unable to have the necessary technological interventions that make their bodies and identity as congruent as possible. His new birth certificate allows him a certain amount of social legitimacy. The transgender community has heralded the GRA as a huge success and it enables people like Gregory to have a private life without any intrusion into his history. Whilst this is extremely positive in Gregory's case it has implications for the sexed birth certificate system in relation to intersexual embodiment and citizenship. If the UK system can cope with bodies of difference, this is a step towards realising that the sex system does not require normative bodies for the birth certificate. It may be an avenue that those opposing citizenship rights based on a two sex model can utilise to demand a rethinking of the sex system.

Concluding Remarks

I do not want to draw any conclusions, but in this exposition I have argued that intersexuals, in many cases, have been subject to surgical and hormonal intervention for the sake of their congruency into a sex system that cannot cope with difference. The fact that the sex system and its apparatus, the birth certificate, functions, and is enunciated through different modalities on different bodies, such as the normative, the transgender and the intersexual, suggests that the logic behind it is being called into question. If the medicolegal sexed system has begun to acknowledge that sex is not based on normative bodies, that some bodies have to be moulded to fit it (intersexual), or that bodies are denied any importance (some transsexuals), surely this undermines the traditional reasons to have a birth record situating a binary sex. What this also questions is the binary notions of man/woman, heterosexuality/homosexuality, and the heteronormative family. What would that mean for sexual and gender citizenship? This chapter does not have the answer, but is an exposition on the possibility of difference in relation to birth certificates, which I argue underpins sexual and gender citizenship.

CHAPTER 11

Advancing Sexual Health of Persons with Disabilities Through Sexual Rights

Godfrey Kangaude

Accessible summary

This chapter discusses sexual health of persons with disabilities through the lens of human rights, and more specifically the concept of sexual rights. One of the hurdles persons with disabilities experience in their sexual health is the stigma of asexuality. This is reflected in the social and legal policies which have constructed persons with disabilities as asexual.

The chapter highlights the following about the sexuality and sexual rights of persons with disabilities:

- Throughout history, persons with disabilities have been treated as persons who are not sexual
- Understanding sexuality as socially constructed has enabled persons with disabilities to demand that society respects their sexual needs
- Sexuality is central to humanity and persons with disabilities are not less human
- The stigma of asexuality has an impact on the sexual health of persons with disabilities
- The concept of sexual access advanced by Shuttleworth helps us focus on the sexual needs of persons with disabilities
- Sexuality of persons with disabilities should not be seen as secondary to their other needs such as education and economic empowerment
- The human rights philosophy is an important vehicle for advancing the sexual health of persons with disabilities
- The concept of sexual rights is a powerful tool to expose the relationship between human rights and the sexuality of persons with disabilities
- Human rights instruments must be interpreted and re-interpreted to include persons with disabilities as full sexual subjects

Persons with disabilities are today still discriminated against and considered as persons without sexual needs. Governments and society need to adopt policies and laws that counteract rather than perpetuate this stigmatization. This will be one way that society can ensure that persons with disabilities also enjoy the fullness of sexual health from which they have been frequently been excluded.

Introduction

At the inception of the modern international human rights movement, persons with disabilities did not immediately emerge as a group deserving special rights protection. It was through political negotiation by activists that persons with disabilities progressively gained recognition in the human rights discourse, culminating in the adoption of the recent Convention on the Human Rights of Persons with Disabilities (hereinafter 'the Convention').

Even as persons with disabilities have gained recognition as full citizens deserving equal opportunities, they have not fully emerged as sexual citizens in the human rights arena. The stigma of asexuality still presents a hurdle to their realisation as full sexual citizens. This stigma has usually been reflected in social and legal policies which have constructed persons with disabilities as asexual.

This work explores the stigma of asexuality and its relationship to the heteronormative value system. It examines the impact of this discrimination on the lives of persons with disabilities through the concept of sexual access advanced by Shuttleworth. It examines the complicity of social and legal frameworks in perpetuating the stigma.

It is submitted that in order to advance the sexual health of persons with disabilities, the primary challenge of states is to deal with the insidious stigma of asexuality. Policy and legal frameworks must reflect the obligation and commitment of states to advance the sexual rights of persons with disabilities.

Constructing Disability

There are various constructions of disability including the biomedical and social models but also the post-modernist construction.

The medical model conceives disability as impairment and focuses on deviation from normality. Persons have a disability insofar as they have deviated from this normality (Shakespeare 1996a).

The medical model still has a powerful influence today. Smart and Smart (2006: 30) say that the biomedical model carries the power and prestige of the medical profession which commands respect. This is one reason why disability seen through the medical perspective has gained a strong foothold in Western Societies. Influence of the biomedical model has affected African societies with the arrival of Western medicine on the continent.

Locating disability in the person and conceiving disability as an objective condition subsisting in the person resulted in discriminatory treatment (Rioux 1994: 70-71). Since the medical model focused on 'treatment' of disability, inevitably this drive to eliminate disability conflated with exclusion or elimination of persons having the disabilities. This was achieved through institutionalisation, segregation of schools, asylums and sheltered workshops.

The stigma and discrimination against persons with disabilities was also encouraged by the science of eugenics. This was to have one of the harshest effects on persons with disabilities because they were thought to be reservoirs of undesirable traits and genes. Rioux noted that:

The enthusiasm of the eugenicist and psychometricians for finding a scale to measure innate difference was translated into scientific evidence of inferiority and superiority. In the hands of governments and lawmakers, the scale became a means to differentiate and justify unequal treatment, including the restriction of basic citizenship rights such as procreation, marriage, immigration, education, property ownership and ability to contract (Rioux 1994: 72).

The stigma surrounding the sexuality of persons with disabilities was therefore legitimised by science. Denying their sexuality or imputing a perverted sexuality were just two sides of the same coin justifying the social and legal control of their opportunity for sexual activity and expression, and most importantly procreation. One way of perpetrating this was through involuntary sterilisation. This mentality is reflected in the case of *Buck v Bell* (1927) where Justice Oliver Wendell Holmes of the United States Supreme Court made the following statement in favour of the sterilisation of a person with a mental disability.

It is better for all the world if instead of waiting to execute degenerate offspring for crime, or to let them starve of imbecility, society can prevent those who are manifestly unfit from continuing their kind... three generations of imbeciles are enough (Buck v Bell 1927: 207).

The influence of the medical model is evident in the legal control of the sexuality of persons with disabilities. For instance the Penal Code of Malawi, which is one piece of legislation transplanted from English law in 1930 and still in effect today, captures the stigma against women with mental disabilities where it says that:

Any person who, knowing a woman or girl to be an idiot or imbecile, has or attempts to have unlawful carnal knowledge of her under circumstances not amounting to rape, but which prove that the offender knew at the time of the commission of the offence that the woman or girl was an idiot or imbecile, shall be guilty of a felony and shall be liable... (Penal Code 1930).

In the name of protecting girls and women with mental disabilities, legal policy treats them as objects without sexual agency.

The social model arose primarily as a critique of positive science as the dominant discourse which organises and influences how the society conceives phenomena. The social model of disability was therefore a reaction to the biomedical model (Diedrich 2005: 653-654).

The social construction of disability enabled civil rights movements including the disability movement to frame their political concerns in terms of human rights. The disability movements insisted on entitlement of persons with disabilities to full citizenship rights (P Cole 2007: 174). They criticised policies and laws that were based on the medical model, perpetuated negative stereotypes, and justified the exclusion of persons with disabilities from the benefits of citizenship (Barton 1996: 13-14, Prince 2004: 462-463). Removing social barriers and achieving equality was central to the project:

Without a concept of social barriers to full participation in society, a movement from the welfare approach to a rights-based legal paradigm would not have been possible. People

with disabilities could not be conceived as equals while there was automatic assumption of inferiority and incompetence (Jones and Basser Marks 1998: 6).

The biomedical and the social models have contributed to the conceptualisation of disability and continue to be influential in social policy and law (Ngwena 2006: 646). Rehabilitation programs are certainly important. It remains important to protect girls and women with intellectual disabilities from sexual abuse. Therefore, an integrated approach that combines both models greatly enhances the potential to empower persons with disabilities. It also allows disability to be a subject of human rights.

However, postmodernist thought has critiqued the social model of disability as inadequate because it attempts to:

seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people's lives and of their knowledge (Corker and Shakespeare 2002: 15).

It is argued that the social model as a unitary concept cannot possibly capture the diversity of impairments and the individual experiences of persons with disabilities across a diversity of social locations.

The same criticism in different words is was made by Hughes and Patterson (1997) who highlighted the fact that the social model is based on the separation between body and culture, impairment and disability and in so doing, "the body as a social and historical construct, and as a site of meaning and purposive human action is lost" (Hughes and Paterson 1997: 330).

This work therefore acknowledges that the social model much as it is still influential does not have the final say on disability, though the move from the medical model to the social model did provide an impetus for the disability movement to frame the citizenship claims in an emancipatory language and using the language of human rights.

Sexuality and Persons with Disabilities

Defining sexuality

Sexuality is a term imbued with many meanings (Weeks 1986: 11-18). The complexity of the term behoves an exploration before presenting a definition adopted herein.

To begin deconstructing the term, the different philosophical underpinnings of its conceptualisation need unravelling. Perspectives that have shaped the understanding of sexuality include essentialism and social constructionism.

Essentialism implies the belief that certain phenomena are natural, inevitable and biologically determined (DeLameter and Hyde 1998: 10). From this perspective, sex and sexuality are intricately linked to reproduction, and women's sexuality to motherhood. One consequence of such conceptualisation is the institutionalisation of heterosexuality, where family

and marriage are the privileged sites of sexual intercourse and child-rearing (Carabine 2004: 6).

From the social constructionist perspective, sexuality is not a biological given but is socially and culturally constructed (DeLameter and Hyde 1998: 13, Esplen 2007: 2). Sexuality therefore is a social construct whose meaning is derived from language or discourse; a way of thinking and talking about behaviours that are considered sexual or not sexual (DeLameter and Hyde 1998: 15). Carabine (2004: 8) also says that the social constructionist perspective emphasises the social meanings which an individual attaches to specific sexual acts, behaviours, feelings, desires and relationships.

Another feature of sexuality is that it is experienced at the individual and personal level as well as the social level. Carabine says that:

At a personal level, sex and sexuality may invoke different sets of ideas and feelings in us to do with intimacy, privacy, pleasure, desire, embarrassment, attraction, age, fear, pain, abuse, control, freedom, fulfilment, danger, constraint, disease, well-being, our bodies, love and emotion (Carabine 2004: 2).

At the socio-cultural level, sexuality is constructed to serve a variety of needs: sex is a means of procreation, an intimate bonding ritual, even a form of social control (Rye and Meaney 2007: 29). It is this characteristic of being private and at the same time public, arising as a biological given and at the same time socially constructed, that sexuality is a highly contested and contradictory terrain. Its malleability and capacity to evoke varied usually invokes fierce political and public debate (Carabine 2004: 2).

Ultimately, a useful definition would try and capture these aspects of sexuality. The working definition by WHO international and technical consultation on sexual health affirms the complexity of the term:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, religious and spiritual factors (World Health Organisation 2004).

The WHO definition recognises that sexuality is a central aspect of being human. It also recognises that the social, legal and other factors influence sexuality. An example of this influence is explored in how society, in interaction with social and legal policies, constructs persons with disabilities.

Persons with disabilities and the myth of asexuality

The stereotype that ascribes asexuality to persons with disabilities is a general phenomenon. Following from the definition of sexuality, asexuality means lack or deficiency to express or experience any one or more of the elements constituting sexuality.

The myth of asexuality has adverse effects on the sexual wellbeing of persons with disabilities. Shakespeare et al in their ground-breaking book have provided an insightful account of the impact of this denial of sexuality on the wellbeing of persons with disabilities (Shakespeare *et al.* 1996). Persons with disabilities face various hindrances to live their sexuality to the full. This includes lack of sexual self-esteem, failure to enjoy pleasurable sex and failure to get sexual partners (Hamilton 2002, Tepper 2000b, Yoshida, Li and Odette 1999). Their access to sexual expression may be limited or excluded (Shuttleworth and Mona 2002, Wade 2002). They generally experience higher levels of sexual abuse (Naidu, Haffejee, Vetten and Hargreaves 2005). They are thought of as incapable of consenting to sexual relationships so that they are on one hand protected by the law from sexual abuse, but on the other denied sexual relationships (Evans and Rodgers 2000). The health care system may fail to address their sexual needs (Kvam and Braathen 2006). Women with disabilities are thought of as being incapable to be good mothers (O'Toole 2002).

Weeks reminds us that sexuality is socially regulated by traditional mores, customs and other non-state systems (Weeks 1986: 29-31). However, legal and social policies play a role in shaping sexuality. Generally, it is only when sexuality is perceived as a problem that policy and law make appearance, as in the case of homosexuality, the sexuality of persons with mental disabilities and under-age sex. Regulation of sexuality comes in the form of protecting vulnerable individuals from undesirable and unwanted sexualities, through criminal legislation, sex education policies, and disability policies (Carabine 2004: 2).

Policy and law do not maintain silence on sexuality because there is nothing to say. Rather, argues Shildrick, the silence implies the assumptions of dominant constructions of sexuality. Silence may actually construct persons with disabilities as asexual (Shildrick 2007: 54-56). The dominant construct posits as the norm the heterosexual relation between two putatively equal adults, whose sexual practice is primarily genital based, procreation oriented and conducted in private (Shildrick 2004: 131).

Shildrick therefore argues that social and legal policies always have some form of regulation on sexuality. Generally, persons who exhibit sexuality that conforms to heteronormativity have the benefit of the positive aspects of this regulation. One definition of heteronormativity is provided by Asia Pacific Forum on Women, Law and Development (APWLD): "... the privileging of heterosexuality and the prescription of marriage and reproductive sex as the only accepted form of sexual relations..." (APWLD 2007: 24). Due to disability, persons may have a body morphology or intellectual development that makes them unable to experience penetrative sex, verbally communicate their needs and desires, not able to conceive, produce sperm or need physical support to be able to engage in sexual activity. When the

sexuality of persons fall outside the normative range, then their sexuality is not recognised (Shildrick 2004: 135).

The stigma of asexuality depends on the impairment. It is not merely that the disabled body may not be aesthetically appealing according to social meanings of attractiveness, though that may be part of the reason persons with disabilities may experience stigma. However, one determining factor of the stigma is the extent to which the disabled body or intellect has the potential to, or actually challenges the dominant norms governing sexuality. When disability subverts the heteronormative values and hegemonic masculine expectations (Shuttleworth 2007a: 189) of the society, it is bound to be stigmatised. However, this is not to say that heteronormative sexuality is never stigmatised, but to argue that one reason persons with disabilities are stigmatised is because their sexuality may fall outside the heteronormative.

As Wilkerson says:

If heterosexual vaginal intercourse is taken as the norm, the sexual practices of many will not seem to count as sex at all. Knowledge of diffuse male sexualities may be culturally suppressed, or even incomprehensible, because they are perceived as incompatible with masculinity, while for women such pleasures are perceived as outside the domain of legitimate heterosexual experiences. The repercussion for those with physical disabilities, like many others, may be silence and unintelligibility, their sexualities rendered incoherent, unrecognisable to others or perhaps even to themselves, a clear instance of cultural attitudes profoundly diminishing sexual agency and the sense of self and personal efficacy which are part of it (Wilkerson 2002: 48).

The stigma is stronger where the impairment is more severe. It should also be realised the oppression of this stigma intersects with other oppressions such as gender, age, socioeconomic status and race (Shuttleworth 2007a: 176). This complicates the study of sexuality and disability. However, the current work is pitched at a general level and will therefore not delve into these other facets of oppression.

Shildrick calls attention to the fact that social and legal policies, and sexuality are mutually constitutive in that they shape each other. In other words, change in how policy constructs sexuality may redefine how persons understand sexuality. Conversely, how persons understand their sexuality may force policy to revise its construction of sexuality (Shildrick 2004: 143).

This means that change to improve the acceptability of the sexuality of persons with disabilities may happen at two fronts. Policy may be formulated in such a way that it does not construct persons with disability as asexual, or the disability movement may through a better understanding of sexuality apply pressure on policy-makers to take into account the fact that policy has an impact on how society will accept the sexuality of persons with disabilities.

The myth of asexuality robs from persons with disabilities a central part of their humanity. When policies maintain a construction of sexuality that defines persons with disability as asexual, they perpetuate the stigma.

Persons with disabilities and disability movements can challenge the stigma and pressurise policy to construct sexualities that legitimise their experiences and their being sexual subjects. The interaction between policy and sexuality is further examined through the concept of sexual access.

The concept of sexual access and persons with disabilities

Activism that saw the paradigm shift from disability understood as a biomedical problem to disability as a social problem also gave momentum to advocacy for recognition of the sexuality of persons with disabilities. However, Shuttleworth argues that there has not been adequate focus on what is central to the sexual needs of persons with disabilities. He therefore introduces the concept of sexual access as a tool for focusing the discussion on sexuality (and sexual rights) of persons with disabilities.

The concept is premised on the recognition that first and foremost, the stigma of sexuality places restrictions on persons with disabilities in their attempt to negotiate sexual relationships with others (Shuttleworth 2007a: 178). However, sexual access is not just about physical intimacy:

By sexual access we do not mean access to physical intimacy per se. Rather, we mean access to the psychological, social and cultural contexts and supports that acknowledge, nurture, and promote sexuality in general or disabled people's sexuality specifically (Shuttleworth and Mona 2002: 3).

Shakespeare states that the inability of society to nurture the sexuality of persons with disabilities, hinders sexual access and results in poor self-esteem (Shakespeare 2000: 161).

Sexual access can be broken down into two aspects. The first aspect of sexual access is the psychological, social and cultural supports that acknowledge and nurture sexuality and the individual's need for sexual expression and experience of intimate relationships. The second aspect of sexual access encompasses the opportunity for an encounter with the other. The person should have the opportunity to access the social and interpersonal space in which mutual desire is evoked and sexual negotiations become possible (Shuttleworth 2003).

The following illustration captures the concept. While non-disabled children are groomed for future relationships, the disabled child may be ignored and thus fails to learn the skills of interacting with potential sexual partners. Even if the now grownup person gets a chance to meet a potential sexual partner, the earlier social and emotional exclusion will affect the possibility of creating a healthy sexual relationship, because he or she lacks appropriate interaction skills (Shuttleworth 2001: 105).

The notion of supporting sexual access of persons with disabilities is certainly one that rouses controversies and with potential to evoke highly emotionally charged discussion within, without and across the disabled and non-disabled communities. These include facilitated sex (Davies 2000b, Shuttleworth 2007b, Tepper 2000a) and sexual surrogacy (Shapiro 2002: 81). Despite what the controversies these ideas may churn, Shildrick comments that:

Whether you are able-bodied or disabled, you may find the idea of facilitated sex shocking, commendable or immoral. ... One thing is sure: however we view the dilemmas, the idea of facilitated sex does not force us all to acknowledge the sexuality of disabled people (Shildrick 2004: 153).

Sexual access of persons with disabilities should therefore not be ignored because this challenges certain reified norms. At stake is the humanity of persons with disabilities. They are sexual subjects too.

Disability movements and sexuality

Disability movements around the globe, most especially in the developed Western countries, have taken up the struggle for a positive affirmation of sexuality. Claims have been made that governments should fund sexual encounters for them (BBC News 2005a). Organisations have facilitated sexual encounters for persons with disabilities (Ilkcaracan and Jolly 2007).

However, the general trend in Africa is to dwell on the prevention of violence and HIV and AIDS though some few voices have articulated the affirmation of sexuality as important for persons with disabilities (Barry 2006: 65-67, Zambé 2006).

For instance an activity which is enjoying prominence and spearheaded by the African Secretariat of the African Decade for Disabled Persons through its Continental Plan of Action is the campaign against HIV/AIDS. A booklet made for the campaign states:

The stigma experienced by persons with disabilities means that they are less likely to marry and more likely to have several sexual partners in a series of unstable relationships (Secretariat of the African Decade of Persons with Disabilities no date).

In the African context where it is assumed that the male is the one who goes out to seek sexual partners while the woman is a passive actor, it almost seems as if the statement is made with the man in mind. It also seems to assume that persons with disabilities are able to find sexual partners and engage in sexual intercourse with them. This statement therefore seems to be biased towards the masculine gender and assumes heteronormative sex as the norm. This excludes certain persons with disabilities who pale into invisibility as sexual subjects because they may not marry or indeed access partners in some relationship involving penetrative sex.

Despite glossing over issues of sexuality, evidence from the Africa region indicates that young people with disabilities experience rejection from adults and peers, and exclusion from information sharing regarding sexuality (Motalingoane-Khau 2006). This also reveals how the myth of asexuality damages the self-esteem of young disabled persons (Potgieter and Khan 2005).

Sexuality of persons with disabilities has therefore not been brought onto the socio-political forum in the African region. The general picture is that the discussion of persons with disabilities makes appearance primarily in

discussing HIV/AIDS, reproduction or sexual abuse. Otherwise persons with disabilities tend to be invisible as sexual subjects.

There may be several reasons for this. One is that sexuality is a taboo and to bring up the topic for discussion in public, even for persons who are non-disabled is not easy (Malawi Human Rights Commission 2006). Shakespeare brings up another:

I think that sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level – both acceptance of oneself, and acceptance by significant others – and forces people to confront things which are very threatening, given the abusive and isolated lives of many disabled people (Shakespeare 2000: 160).

Yet another reason may simply be that sexuality is not considered as important in the light of concerns that are considered more pressing such as poverty, education and employment. Shakespeare reacts to this thinking that sexuality, poverty, education, employment and all are interwoven so that sexuality cannot be trivialised in relationship to the other needs and concerns of persons with disabilities (Shakespeare 2000: 206). Actually, sexuality may be the core that holds all together as in the end we are all looking for satisfaction that comes not only with employment and education but with intimate relating with persons of our choice.

Persons with Disabilities as Sexual Subjects in the Human Rights Discourse

The concept of sexual citizenship

Citizenship is still a debated concept and therefore defined from different points of view. Richardson considers it a key concept that has re-emerged in social theory, and has been used to critique the traditional discourses governing the rules of belonging to a particular society or nation (Richardson 2000b: 255).

The starting point for the modern definition of citizenship comes from Marshall who defined citizenship as a status bestowed on those who are full members of the community, consisting of certain rights and duties (Lister 1997: 29). These members of the community enjoy three categories of rights: civil or legal rights, political rights and social rights (Richardson 2000b: 140). The essence of citizenship is belonging or membership to a polity with the associated rights and duties that flow from this belonging. Social and legal policies and rules that govern this relationship between the government body of the community or state, and the members, as well as the relationship between the governing body of the community or state, and the members, as well as the relationship between members (Isin and Turner 2007: 13).

Nyamu-Musembi distinguishes between formal and substantive citizenship. She calls the linear relationship between the state and citizens formal citizenship. Substantive citizenship on the other hand goes beyond the

confines of formal politics and law to encompass the economic, social and political relationships amongst informal structures of power that govern rules of belonging. These mediate one's experience of formal citizenship (Nyamu-Musembi 2007).

Citizenship as a political concept has gained ground in the sexuality discourse, giving rise to the concept of sexual citizenship. The idea of sexual citizenship has been used to question the exclusion of certain groups from enjoying the status of citizenship due to their sexual identities. This has been pioneered by feminists who have challenged exclusion on the basis of gender (Goetz 2007, Horn 2006). It has also been used by gay, lesbian and queer activists to challenge exclusion on the basis of sexual identity (D Bell and Binnie 2000, Donovan 1999, Kaplan 1997, Mulé 2006). It is also being used to challenge exclusion based on disability (Sherry 2004: 769-783).

This work adopts the argument by Bell and Binnie that citizenship is always sexualised (D Bell and Binnie 2000: 10). Shildrick also comes to the conclusion that no one, whatever their form of embodiment, escapes the web of regulatory power that is directed towards all aspects of bodily identity, comportment, and behaviour. Thus persons are already marked out as one sort of sexual citizen or another (Shildrick 2004: 62).

Therefore multiple forms of sexual citizenship coexist. There is mainstream naturalised, heteronormative modality of citizenship. Against this there are other citizenships such as gay citizenship or queer citizenship. The heterosexual marriage is given a privileged status in society as the institution where persons can have acceptable sex and procreate. This is sanctioned by legal and social policies through marriage laws. According to the heteronormative ideology, the values of good citizenship are produced in heterosexual marriage such as discipline and selflessness. Other unions such as homosexual unions are looked down upon as promoting narcissistic preoccupation with non-procreative sexual pleasure (Stychin 2003: 11-12).

This hierarchical arrangement of sexual citizenship marginalises those who do not conform to heterosexual norms because of sexual identity, but also because of disabilities. In order to ensure full sexual citizenship for persons with disabilities, the privileged status of the heterosexual citizenship ought to give way to other models of sexual citizenship that will embrace the diversity of sexualities. Persons with disabilities must enjoy equal opportunity to sexual access. Sexual citizenship should be grounded in principles of human rights including sexual rights.

Sexual rights

The origin of the modern conceptualisation of sexual rights is traced to the two world conferences, the International Conference on Population and Development (ICPD) of 1994, and the Fourth World Conference on Women (FWCW) of 1995. The Beijing Platform for Action defined sexual rights in the following terms:

The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence.

Petchesky and others have criticized the above definition for placing sexual rights under reproductive rights and conflating the two (Miller 2000: 86-88, Petchesky 2006). This, they claim, tends to diminish the importance of sexual rights. One reason for this is that issues to do with sexuality are more politically sensitive than those that deal with reproduction. In fact the term 'sexual health' is more palatable politically than the term 'sexual rights'. The former appears in the consensus documents from the ICPD and the FWCW and others, while the latter does not (Correa 1997: 109).

However, sexual rights are not new rights, but rather existing rights applied to sexuality (Klugman 2000: 153). Sexual rights have always been there, only that it was the privileged citizen, the heterosexual, non-disabled male who enjoyed full sexual citizenship (Richardson 2000a: 75). Horn for instance says that in the patriarchal African Society, the ideal woman is heterosexual, married in order to bear children and please her husband sexually (Horn 2006: 9). Further, Africa in general is hostile to sexual expression that is not heterosexual.

It is thus not surprising that feminists, gays and lesbians and other marginalised groups have been in the forefront in the struggle for recognition of sexual rights (Eager 2004: 152-169). Their political agenda being perceived as subversive to traditional sexual norms, has met fierce resistance (Long 2005). Persons with disabilities face similar hurdles in their quest for respect of their sexual rights.

Persons with disabilities as subjects of sexual rights under international human rights

If non-disabled persons have had to fight for recognition of their sexual rights, it has been worse for persons with disabilities who have to overcome the stigma of asexuality. However, with the adoption of the Convention, the sexuality of persons with disability has been given some attention though it is still a long way to achieve realisation of their sexual rights.

International human rights treaties prior to the Convention have shied away from recognising persons with disabilities as subjects of sexual rights. A survey of some human rights treaties and especially specific provisions reveals this exclusion. The discussion below selects some categories of rights that have a bearing on sexual access for persons with disabilities.

The first category of human rights relates to the right to marriage and family. These include article 23 of the Convention, article 23 of the ICCPR, article 10 of the ICESCR, article 6 of the African Women's Protocol and article 16 of CEDAW. These articles in varying verbatim recognise the right of all persons to enter into marriage freely and without coercion. However, the context of the articles which mention children and reproduction are more aligned with the thinking that sex is for reproduction and therefore may tend to exclude sexual experiences that do not necessarily end up with penetrative sex or bearing of children.

Further, in General Comment No. 19 of the Human Rights Committee, it is said that the right to found a family implies the possibility to procreate and live together. However despite this observation, the Human Rights Committee leaves open the definition of family. It is argued that the Committee implicitly acknowledges diversity of sexualities that do not necessarily imply procreation and child-bearing nor permanent cohabitation.

The Committee on the Social, Economic and Cultural Rights in its General Comment No. 5 says that laws and social policies and practices should not impede the realisation of the rights of persons with disabilities to marry and form a family. It has been noted that:

General Comment No. 5 reiterates Rule 9(2) of the Standard Rules, stating that 'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood'. It then stresses that 'the needs and desires in question should be recognised and addressed in both the recreational and the procreational contexts' (Quinn and Degener 2002).

The Convention does not explicitly mention sexuality and sexual relationships. Only in the context of sexual health is the term 'sexual' mentioned and in conflation with reproductive health. Otherwise, it mentions the right of persons with disabilities to marry and have a family, which *prima facie* is a narrower context than sexual relationships. This potentially excludes the experience of other sexualities which do not necessarily lead to marriage and procreation.

The second category of human rights provisions related to health. Some mention sexual health specifically such as article 25 of the Convention and article 14 of the African Women's Protocol. Though others mention health in general, it is submitted that these incorporate sexual health as well such as article 25 of the UDHR, article 12 of the ICESCR, and article 12 of CEDAW. Arguably, these bear the closest relationship to affirming sexual wellbeing of persons with disabilities through the concept of sexual health. These have an important bearing on sexual access, and guarantee persons with disabilities the right to sexual relationships, activity and pleasure free of coercion and disease. They refer to correlative rights articulated in various human rights provisions including the right to information and communication on issues such as HIV/AIDS and related sexual and reproductive health matters.

One caution here is that conflation of sexuality and reproduction tends to take attention away from the sexual in favour of reproduction. This, as already stated above, may exclude subjects whose main obstacle lies in the sexual such as persons with disabilities who face the stigma of asexuality.

Another caution is that reference to health may medicalise sexuality of persons with disabilities. An example is with male impotence. Much as persons can derive benefit from treatment of impotence, Shuttleworth and others have warned against this being a guise for perpetuating the thinking that these people need to be fixed so that they fit the traditional expectations of the male species, ie a person who can partake in penetrative sex and procreate (Shuttleworth 2004b, Tiefer 1994, Wentzell 2006).

Provisions relating to childhood are also important with regard to sexual access, for instance article 23 of the CRC and article 13 of the African Children's Charter. The Convention has a provision on children couched in terms of full enjoyment of rights, best interests of the child, and freedom to express views. Sexuality is not mentioned because children are generally not regarded as sexual subjects. However, sexuality must be read in. Despite being thought of asexual till the age of maturity, a child is normally groomed

for social interaction which includes sexual relationships. Foundations of sexuality are laid down at the childhood stage, and therefore sexuality cannot be ignored until age of maturity is attained. Seeds of self-worth and sexual self-esteem are sown long before the person reaches maturity (Shakespeare *et al.* 1996: 17-19).

The point that is being made here is that human rights instruments must be interpreted to include the sexuality of persons with disabilities. This may raise issues potentially subversive to the status quo. It forces society to open up to what Petchesky argues should be the vision of sexual rights (2000: 126-128). She says that this must embrace ethical principles which include diversity, health and autonomy. Sexual diversity implies commitment to the principle that diverse types of sexual expression are not only tolerable but beneficial to a just, human and culturally pluralistic society. Habitational diversity recognises that all sorts of families and cohabiting groups, regardless of structure are entitled to receive comprehensive protection from the state. Health involves enjoyment of satisfying and pleasurable sexual life. Autonomy recognises agency of the sexual subject.

The obligation of states therefore is to create conditions in which sexual rights can be achieved. It is submitted that this includes creating conditions which will counter the stigma of asexuality directed towards persons with disabilities.

Conclusion

Having argued a case for sexual rights of persons with disabilities, it is appreciated that more is needed to address the sexual needs of persons with disabilities than fixing social and legal policies (C Barnes 1998). Shildrick argues that changing the law and granting sexual citizenship should recognise the irreducible differences amongst sexual subjects which generate diversity of sexualities. She cautions that glossing over such differences risks continued marginalisation of those who are considered to be too radical for inclusion (Shildrick 2007: 64).

Sexual rights are still not fully realised for various other groups including women and adolescents. This is why some organisations in the Americas are campaigning for a convention specific for sexual and reproductive rights because there is a lack of clear articulation of these rights in a standard-setting human rights instrument (Pandjarian 2003: 77-81). Human rights and disability movements can act in synergy to bring about transformation of attitudes that will overcome the stigma of asexuality.

Allowing persons with disabilities to enjoy full citizenship requires a change in how society constructs sexuality and disability. There is bound to be resistance to move forward from a heteronormative mentality that confines sexuality to penetrative sex and procreation and trivialises the diversity of sexualities that would encompass the wider society including persons with disabilities. However, social policy and law should not perpetuate stereotypic thinking. Even if change in the in policy or law may not immediately transform fundamental attitudes, it has constitutive and symbolic importance. Adapting policy and law to incorporate full sexual citizenship is bound to have an important bearing on the society. Disability movements therefore must urge governments to adopt policies and laws that counteract the stigma of asexuality.

It is certainly important that governments must pass enabling policies and legislation to raise the social and economic status of persons with disabilities such as enable them to attain good education, alleviate poverty, secure employment and so on. These do contribute to general wellbeing including sexual health. However, sexual rights for persons with disabilities ought to be advanced in their own right as well. Given the ideological quagmires which face this, it would perhaps be unrealistic to expect monumental strides. Sexual rights might not be gained in awe-striking quantum leaps. However, as has been said in different words by scholars in field of disability such as Shuttleworth and Shildrick, the realisation of sexual wellbeing of persons with disabilities may not so much lie in the achievements gained at a particular stage, but on whether the struggle for recognition is kept alive by the dialectical tension between claiming of sexual rights and the social reflection (and not dismissal) on the emergent sexualities that constantly challenge reified norms.

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