

SEXUALITY AND DISABILITY:

A COMPARISON OF THEMES FOUND IN THE SEX AND DISABILITY LITURATUE

By

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ABSTRACT

The purpose of this investigation was to explore the issues of people with disabilities regarding their sexual development and sexual expression. This thesis adds to the growing body of literature regarding the sexuality of people with disabilities by highlighting the complexity of accommodating the sexuality of people with disabilities into society. Four major topics are explored: barriers, advocacy, sexual identity, and ethics. The individual sexual experiences of people with disabilities often runs counter to the broad-based assumptions faced by those individuals.

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My mother and father

My many friends who live with disability

And

My darling Claire who has been waiting so patiently for me to finish this exercise.

DEDICATIONS

To those determined to value the authenticity and autonomy of those struggling with all forms of sexual oppression.

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CHAPTER I INTRODUCTION

This thesis will examine issues surrounding the accommodation of sexual development and expression of people with disabilities (including congenital, chronic illness, traumatic injury, and psychiatric). There are barriers to that development and expression that relate to the effects of disabilities and the socially constructed concept of disability itself. Inherent to the issue is that people tend to make broad assumptions regarding people with disabilities in relation to their sexuality. Given these two points, this thesis will argue that the individual experiences of people with disabilities often runs counter to broad-based assumptions.

I intend to explore and articulate the issues facing the intrinsic sexual agency of people with disabilities, agency which is tied to their dignity and worth as human beings. People with disabilities have the right to their sexuality and sexual expression; therefore, it is the duty of society to accommodate that development and expression. This thesis adds to the growing body of literature regarding the sexuality of people with disabilities by highlighting the complexity of that accommodation. This chapter will focus on reviewing the literature regarding barriers to sexual development faced by people with disabilities. This will only be an overview of those barriers as an in-depth review would take up the entire length of a thesis. It is further important to note that people with disabilities are not a uniform culture or population; they are as diverse as any other, but bound to a category due to social perceptions of disability.

Background

Sexuality must be viewed in the broadest sense: sexuality is not only the physical act of copulation or sensual pleasure, but also includes the ways in which people present themselves to others, the ways one perceives others, and interactions within the social landscape (Sipski & Alexander, 1997). It includes the way one expresses companionship and love, as well as aspects of personality and emotional existence that express maleness and/or femaleness. The importance of sexuality cannot be overstated: most people with and without disabilities report that sexuality and its expression are a natural and important part of self-concept, emotional well-being, and overall quality of life (Felce & Perry, 1997). And sexuality, due to its connection to self-esteem and body image (as well as other factors), has been suggested as an important part of rehabilitation (Sipski & Alexander, 1997). Development toward sexual maturity is regarded as a necessity and developmental success or failure of the sexual systems can significantly influence the transition into adult life (Greydanus & Omar, 2008). People with physical disabilities report greater sexual and reproductive disparities as well higher rates of sexual distress than the general population (Rowen, Stein, & Tepper, 2015). And sexual problems of various kinds are more common among people with disabilities than peers without disabilities (Kedde, Van De Wiel, Schultz, Vanwesenbeeck, & Bender, 2012).

Sexual development is a complex process that includes the biological maturation of sexual organs and biological systems as well as psychological constructs like gender identity, gender roles, and sexual orientation (LeVay & Valente, Human Sexuality, 2006). The development of these systems is thought to be particularly critical during childhood and adolescence (McKenzie & Swartz, 2011). Sexual development is thought to involve a number of social dimensions and “sexuality continues to be a core and profound component of humanity in which human beings need other humans.” (Greydanus & Omar, 2008, p. 1315). While some people with disabilities

experience physiological complications or variations to sexual development due to their disabilities, it is often found that socio-cultural barriers related to disability that are more difficult to manage (Di Giulio, 2003). Societal attitudes towards the sexuality of people with disabilities can be highly stigmatizing, effecting confidence, desire, and ability to find a partner—harming one's sexual self-concept (Esmail, Darry, Walter, & Knupp, 2010).

Sexual Development

Some propose that the ideal path to mature adult sexuality begins with love and tenderness received as an infant and continues throughout the lifespan (Caruso, et al., 1997; Haroian, 2000). The nurturing effect of love and care that an infant receives (or does not receive) is thought to have a long-term effect on the adult ability to later give love and tenderness (Haroian, 2000). Self-exploration and play with others helps to form self-knowledge and social knowledge. Playing can build self-confidence as children try new things, take risks, make mistakes, and make corrections to their behaviour. Cultural views of what is acceptable or not acceptable influence parental involvement, responsibilities, and guidance in the sexual development of their children.

Different disabilities have different and complex effects on sexual development (Sipski & Alexander, 1997). There are four main broad categories of disability: congenital, chronic illness, traumatic injury, and psychiatric (Milligan & Neufeldt, 2001) and each of these will have various influences on sexual development (Sipski & Alexander, 1997). Biological differences underlying the disability, or the medical treatment of that disability, may impact the physical maturation process of puberty (Greydanus & Omar, 2008). For example, Prader-Willi syndrome may cause a delay in puberty for girls and inhibit the growth of the penis in boys, as well as

possibly preventing one (or both) testis from dropping. Other conditions, such as cerebral palsy and neurofibromatosis may cause early pubertal development. The adolescent with a disability may start at a different point and progress at a different pace than the typical teen cognitively, psychologically, and physically (Woodard, 2004).

Sexual Esteem, Sexual Identity, and Self-image

People with disabilities may struggle with the low economic and social value placed upon their body by society (Sait, Lorenzo, Steyn, & van Zyl, 2009). Some authors suggest that sex has been marketed as a domain for white, young, heterosexual, single, non-disabled (Tepper, 2000), physically attractive people (Hahn, 1981) which has potentially limited the pool of available models to draw upon when forming a sexual identity. For example, an examination of popular men's and women's magazines which feature sexual advice suggested that magazines portray "great sex" as achieved through technical, mechanical, and physical factors (Menard & Kleinplatz, 2008). The authors further suggest that these magazines promote sexual and gender-role stereotypes, enforce narrow sexual scripts, and often deliver contradictory and conflicting message to their readers. Extensive research and hypothesizing has gone into developing an evolutionary explanation for sexual selection and mating since Darwin's *The Origin of Species* (Buss, 2003). Sexual strategies are thought to be innate biologically driven biases that nudge humans, like other animals, towards certain characteristics in sexual partners, with some small divergence along gendered traits. These biases are thought to have developed in order to solve evolutionary problems, such that heterosexual men may be more attracted to physical beauty in women as certain traits correlate with fertility. Heterosexual women may be more attracted to cues that suggest a man is a good provider and monogamous in order to offset the costs/risks of

the long gestation period. These innate biases which select against some forms of disabilities may be exaggerated by cultural media which further emphasizes these biases. Pornography, for example, is a common concern regarding idealistic beauty standards and sexual performance, however, one small study suggests that most young men and women readily develop the skills to deal with exposure to pornography in a sensible and reflective manner (Lofgren-Martenson & Mansson, 2010).

Differences in the type of disability a person experiences, and the onset of that disability, may drastically shape how the person experiences it (Sipski & Alexander, 1997). A person with cerebral palsy, a disease from birth, will necessarily experience disability differently from a person who has a brain injury at age 18 or a spinal injury at age 65. For example, someone with a spinal cord injury may suffer burdensome and intrusive thoughts regarding their sexual performance during sexual activity due to a loss of ability (Tepper, 2000). Being physically capable, or more able-bodied, is often highlighted by people with disabilities as a significant limiting factor regarding sexual esteem (Taleporos & McCabe, 2001). A person with a mental disability may experience more difficulty making judgments about sexual situations than a person with a physical disability (Sait, Lorenzo, Steyn, & van Zyl, 2009). Similarly, many young women with physical disabilities report limited dating experience and feeling a lack of confidence and experience in decision making with intimate partners (Roux, Sawin, Bellin, Buran, & Brei, 2007). Overall, people with more severe physical disabilities reported experiencing significantly lower levels of sexual esteem and sexual satisfaction (as well as higher levels of sexual depression) than people with less severe disabilities and people without disabilities (McCabe & Taleporos, 2003). Struggling with social and sexual barriers appears to lead to increased feelings of negativity, in the belief that they are less sexually desirable than an

able-bodied person, and that having a disability seriously limited their sexual expression (Taleporos & McCabe, 2001). The longer a person has experienced a physical disability, the more positively they rate their sexuality even though the severity of the impairment may worsen, suggesting an adjustment process (McCabe & Taleporos, 2003).

Women with spinal cord injuries have reported having concerns regarding their sexual attractiveness, their ability to sexually please a partner, and concerns regarding urinary and bowel control (Nosek, et al., 1996). Body esteem (how one views their body) in women without disabilities has been found to be a strong predictor of a woman's experience of sexual desire (Seal, Bradford, & Meston, 2009) and her experience of sexual satisfaction (Pujols, Meston, & Seal, 2009). Some female adolescents with disabilities may try to prove their femininity and normalcy by engaging in sexual behaviour to offset threats to self-esteem posed by disability, sometimes with unfortunate results like STI's and pregnancy (Greydanus & Omar, 2008). Some research has highlighted that fears of first intercourse, intimacy, and sexual consequences (i.e. pregnancy and STI's), as well as a perceived or actual lack of pleasure, drives a self-imposed abstinence among some women with intellectual disabilities (Bernert & Ogletree, 2013). Knowledge regarding menopause and condom use did not mitigate concerns regarding pregnancy. Bernert and Ogletree highlighted that some living conditions (such as agency-managed group homes) may present a lack of opportunities to engage in healthy, positive sexual experiences or exposure to sexual education.

Many forms of media have presented an extraordinary sense of need among men with disabilities to lose their virginity; one author has referred to this sense of sexual urgency as the "melodrama of virginity" (Eunjung, 2010, p. 335). Men with physical disabilities are more likely

to be single than women with disabilities, and being single with a physical disability is related to lower levels of sexual esteem, sexual satisfaction, and less frequent mutual sexual activity (Taleporos & McCabe, 2003). And in many cases, for men with acquired disabilities, treatments have focused on “assisting the damaged male to regain his potency” (Fiduccia, 2000, p. 168). Indeed, researchers have found support for the assertion that men with physical disabilities may be more genitally focused than women, rating oral sex and nude cuddling to be important whereas women had a stronger erotic focus on deep kissing (McCabe & Taleporos, 2003). While others put it more bluntly: “for the man with a disability with impaired sexual functioning, the realization that he does not match up may be painfully clear.” (Tepper, 1997, p. 139) Performance anxiety and negative attitudes toward sex are common factors believed to be causally related to many sexual dysfunctions in both men and women (McCabe, 2005).

Sexual orientation is a rarely questioned aspect of the sexual lives of people with disabilities—either because they are presumed to be asexual or presumed to be heterosexual (Noonan & Gomez, 2011). Despite the rising approval of same sex relationships in the general public, qualitative studies have thus far shown that people with intellectual disabilities, their parents, and support staff, view homosexuality among people with disabilities as uncommon (Lofgren-Martenson, 2009). One hypothesis to account for this is that young people with disabilities may be reluctant to explore same sex desires because they depend upon the support of caregivers and that caregivers may dissuade them from deviations from “normal” behaviours in order to increase their acceptance in society. Additionally, homosexual behaviours have been reported to be actively marginalized, or discussed in a dismissive manner, by some support staff in group homes and other settings (Thompson, 1994). Gay, lesbian, bisexual, and transgendered youths who do not receive acceptance of their sexuality from parental caregivers are more likely

to experience mental and physical health problems, lower self-esteem, lower social support, more depression, more substance abuse, and suicidal ideation and behaviours (Ryan, Russell, Huebner, Diaz, & Sanchez, 2010). LGBT persons with disabilities may make up a small proportion within a space between two small groups and thus may be unaccounted for due to difficulty in estimating their numbers or status within those two groups (Noonan & Gomez, 2011). For example, a gay man with HIV may be viewed as a gay man in one survey but as a man with a disability in another, but may not be counted as both at the same time.

Physiological Barriers

It is difficult to assess where a distinct physiological impairment begins for a person and to distinguish it from the socially disabling context. Additionally, for one person an impairment may be a major barrier to sexual expression, while for another it may not be a concern at all. That being said, disabilities may have typical impacts on sexual functioning, along with side effects from drugs or medical treatments (Sipski & Alexander, 1997). Disabilities that cause motor impairments or weakness, such as spinal muscular atrophy or muscular dystrophy, may not provide enough motor strength to masturbate to orgasm or to pleasure a partner (McCabe & Taleporos, 2003). Spinal cord injuries may result in erectile difficulties, impairment of vaginal lubrication, reduced sensation, reduced sexual pleasure, and reduced ability to reach orgasm (Sipski M. , 1991). And similar effects may be experienced with multiple sclerosis with the additional knowledge that the condition will likely worsen over time (McCabe, McDonald, Deeks, Vowels, & Cobain, 1996). Lukemia may result in significant fatigue due to the profound impact on bodily functioning, leaving a person without energy for sexual activity (Sipski & Alexander, 1997). Medical interventions, such as the creation of a stoma (a pathway connecting

the bowels to a pouch for excrement outside the body) may extend someone's life, but causes flatulence, stool leakage, and other problems that can affect body image, anxiety, and self esteem (Ayaz, 2009). Interestingly, at least among women with physical disabilities, the severity of the disability has not been found to be significantly related to the level of sexual activity (Nosek, et al., 1996). Though frequency of sexual activity was not related to sexual satisfaction in either gender (McCabe & Taleporos, 2003).

Privacy

Privacy is considered in short supply for many people with disabilities. For example, those living in group homes may lack sufficient time or place to have private sexual relations (Bernert & Ogletree, 2013). Those with terminal illnesses in hospital settings are likely to lack privacy to have sexual or even basic warm comforting touch (Taylor, 2014). Those in assisted living facilities face the irony of having "ideals of privacy, autonomy, and quality of life" listed as a major components of the regulation of such facilities, only to have them undermined by unlocked-door policies, the presences of roommates, room checks by staff, and access to their medical records by staff (Frankowski & Clark, 2009). Close supervision and closely regulated behaviour by parents, as well as limited peer interaction, may significantly reduce the opportunities for children with disabilities to explore their own sexual development or that of their peers in typical fashion (Sait, Lorenzo, Steyn, & van Zyl, 2009).

Perception, Stigma, and the Asexuality Myth

It is often stated that society largely views people with disabilities as asexual (Earle, 2001) often stigmatizing or dismissing the sexual lives of people with disabilities (Esmail, Darry,

Walter, & Knupp, 2010). The myth of asexuality makes disability difficult, as attested to by personal narratives, images in popular culture, the historical context of rehabilitation programs, attitude research, and the difficulty people with disabilities have in finding intimate relationships (Milligan & Neufeldt, 2001). Some suggest that the negative assumptions and attitudes of society can be internalized by people with disabilities, further marginalizing them (Di Giulio, 2003).

Many disability advocates argue that stigma and the construction of society is more difficult to manage than the impact of the disability itself (Crow, 2007). Some have suggested that the myth of people with disabilities as asexual (or as “impulsive” and “oversexed”) is a way of infantilizing people with disabilities, and thus preserving a power imbalance (Earle, 2001), similar to the denigrating stereotypes of black persons as “sexually insatiable”—implying a form of racial weakness resulting from an inability to control sexual urges and behaviour (Weeks J. , 1986). Some have proposed that the concept of sexuality itself has become a form of social control that involves self-monitoring for deviancy (Foucault, 1979). The construct of disability itself may be used to support a norm and power relationship, that “the cultural function of the disabled figure is to act as a synecdoche for all forms that culture deems non-normative” (Garland-Thomas, 2002, p. 4).

Youths with disabilities that are not easily visible to others have been found to have higher rates of sexual activity than those with visible disabilities suggesting that the social perceptions play an important role in sexuality (Greydanus & Omar, 2008). For example, a person with a physical disability may struggle with issues of physical desirability and/or societal beauty ideals (Esmail, Darry, Walter, & Knupp, 2010) and be perceived as having a sexual dysfunction that is so severe that sexual function and gratification appears limited to the point of

being absent or subjugated (Milligan & Neufeldt, 2001). People with intellectual disabilities may be seen as unable to consent to sexual activity due to their disabilities and thus also viewed as unsuitable partners. They may also be perceived as sexually out of control (Gilmore & Chambers, 2010), which is itself a disorder in the form of sexual addiction (Davis, 2012).

Even when a partner may be suitably interested in a sexual or romantic relationship with a person with a disability, sometimes “[t]here was also an overlying ‘fear of being a caregiver rather than a partner’” (Esmail, Darry, Walter, & Knupp, 2010, p. 1151). Those fears may have some prescience: partners who live together where one person has a disability report less frequent sex than partners who live apart (Taleporos & McCabe, 2003). Couples where one partner has acquired a physical disability may find that sexual activity becomes their most significant issue (Yim, et al., 1998).

Regulation, Violation, and Sexual Abuse

Some have suggested a cultural bias that focuses on “regulating the fertility of the dangerous female” (Fiduccia, 2000, p. 168). This pattern may be widespread in various cultures (Eunjung, 2010). Sexual pleasure of women with disabilities is a rarely researched topic, often researchers have limited their studies to “menstruation, fertility, pregnancy, labor, and delivery of babies” (Nosek, et al., 1996, p. 107). Women with disabilities are at a higher risk of sexual abuse, stigma regarding sexuality, and live with a tighter regulation of that sexuality by others (Sait, Lorenzo, Steyn, & van Zyl, 2009). This leads to an ironic problem: simultaneously, women with disabilities are seen as asexual with closely monitored sexual choices, but are also more likely to become pregnant and have children than women without disabilities in their peer group.

Young girls and women with disabilities are particularly vulnerable in both developed and non-developed countries to violating and difficult experiences such as forced sterilization, early use of birth control medications, rape and sexual abuse, and unwanted children (Sait, Lorenzo, Steyn, & van Zyl, 2009). Although both men and women with disabilities have been forced to undergo sterilization procedures, it is predominantly targeted at women with intellectual disabilities (Fiduccia, 2000). A prominent, and recent, example is the controversial case of Ashley X, a prepubescent American female with profound intellectual disability whom underwent a hysterectomy, double mastectomy, and hormone therapy to prevent her growth (Singer, 2007). On the other hand a disabled woman's conscious choice to have children or to be in a sexual relationship may be questioned or denied (Sait, Lorenzo, Steyn, & van Zyl, 2009). Ironically, it has been found that for some women with disabilities, greater levels of negative stereotypes and discouragement about sexuality can lead to greater feelings of sexual desire (Nosek, et al., 1996).

Even among support and leisure staff who work regularly with people with disabilities, a group which shows high levels of positive support for the sexuality of people with intellectual disabilities, sexist attitudes may prevail (Gilmore & Chambers, 2010). For example, men with intellectual disabilities are seen by support and leisure staff as having less self-control over their sexuality than women. While staff members also felt it was desirable for women with intellectual disabilities to have a lower level of sexual freedom compared with their typically developing peers.

Abuse is a significant concern for people with disabilities. Many report elevated rates of sexual abuse among women with physical disabilities and the additional problem that the

disability, or lack of education regarding sexual abuse, may leave the sexual abuses unreported (Nosek, et al., 1994). Additionally, they may rely on a caregiver that is abusing them to meet their daily needs to varying degrees of dependency (Magoon & Meadows-Oliver, 2011). Women with intellectual disabilities, especially those considered “high-functioning,” are also considered to be in a higher-risk category (Quint, 2000). Interpersonal violence (physical, sexual, and/or psychological abuse in a romantic relationship) is reportedly higher in both boys and girls with disabilities in high school than their peers (Mitra, Mouradian, & McKenna, 2013). In residential care, sexual abuse is committed by other residents approximately 40% of the time, and that approximately 90% of the time the perpetrator is a man known to the victim (Patti, 1995). Children with disabilities are proportionally more likely to experience sexual abuse over physical abuse, more likely to not disclose that abuse, and more likely to experience severe abuse from a parent than their peers (Hershkowitz, Lamb, & Horowitz, 2007). Despite these, and many other studies on sexual abuse and other forms of abuse, some suggest that statistical evidence for highly elevated levels of abuse and neglect among people with disabilities is lacking (Govindshenoy & Spencer, 2007).

Various forms of childhood abuse are major contributors to the development of a wide-range of life-long health issues (Felitti, et al., 1998). Among youths with disabilities, the negative effects of sexual abuse (feeling hopeless, suicidal ideation, self-injury, drug/alcohol use, smoking, poorer health, and unhealthy dieting) seem amplified when compared to youths without disabilities with similar experiences (Mitra, Mouradian, & McKenna, 2013).

Health Care

Healthcare providers have a strong influence on the sexuality of patients with disabilities, and that effect can be positive or negative depending on the approach of the provider (Dune, 2012). In a survey of people with muscular dystrophy, 90% of respondents strongly desired that healthcare providers inform them of all aspects of their condition, including sexual, to better equip them to make decision that affect their emotional and sexual ways of life (Poisson & Mathgen, 1977). However, when contacting a health care professional (general practitioners, psychologists, sexologists, social workers, and medical specialists) for sexual concerns, only around 30% of persons with disabilities were satisfied with the results of their consultation or therapy (Kedde, Van De Wiel, Schultz, Vanwesenbeeck, & Bender, 2012). In another study, negative attitudes of healthcare providers regarding the sexual expression of a person with a disability led to an increase in sexual inhibition, which significantly increased the negative impact of neuromuscular disorders on quality of life measures (O'Dea, Shuttleworth, & Wedgwood, 2012).

Barriers encountered in discussions about sex and the sexual desires of people with disabilities often center on embarrassment by either, or both, the client and the health service provider (Browne & Russel, 2005). Additionally, people with various disabilities have reported that shame, shyness, and anxiety prevented them from seeking specialized help for sexual concerns (Kedde, Van De Wiel, Schultz, Vanwesenbeeck, & Bender, 2012). Additionally, some who sought help could not find a suitable professional and others felt that there would be no benefit to seeking help. Motivation for seeking help was based largely on high levels of sexual dissatisfaction, the desire for professional help, and past experience discussing sexual matters with a health professional.

Conclusion

Significant barriers faced by people with disabilities to sexual development and sexuality have been reviewed. Those barriers tend to cluster around social factors related to disability and perceptions of disability rather than purely physiological effects of the disability. Sexual abuse and childhood sexual abuse represent considerable risk factors for the population. Several authors and researchers point out that little research has focused on sexual pleasure in the population of people with disabilities. In many areas of sexuality persons with disabilities may feel limited or excluded from the rest of society; stigma and myths regarding asexuality continue to play a major role in this exclusion. Some of this exclusion may be enforced through surveillance and a lack of privacy afforded to people with a disability, as well as increased regulation and scrutiny. Sexual identities may be fraught with feelings of sexual inadequacy related to performance or attractiveness. Healthcare professionals, the major contacts for sexual health information, may not provide adequate service due to discomfort.

CHAPTER II ADVOCACY AND SEXUAL ACCESS

Advocacy for the sexual development of people with disabilities has hinged on definitions, philosophies of disability, and the advancement of rights confirmed by those labels and definitions (Shakespeare & Watson, 2002). By defining disability as a primarily social phenomenon, rather than a physical defect, advocates have gained significant political traction. New ideas flourished in an intellectual climate that premised that the personal lives of people with disabilities were in fact deeply political (McRuer & Mollow, 2012). These arguments may be shaped and illuminated by Foucault's (1998) notion of "problematization" which explores how domains of thought become political issues which governments can never fully solve. This chapter will explore themes in advocacy regarding disability and sexuality, in particular focusing on the social model of disability. The issue of sexual surrogacy and facilitated sex will be used to highlight the limited capacity for political solutions as well as the hidden normative assumptions and political nature of sexual research.

Defining Disability

Definitions have been at the center of contentious issues for the disability movement. Advocates sometimes push for rights and improvements through the use of definitions and labels and the rights that those labels confirm (Shakespeare & Watson, 2002). For example, a focus on *impairment* and *disability* mark some of the major trends in philosophical arguments that lead to conversations of rights. The World Health Organization provides the following definitions: "Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function. Disability: Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." (United

Nations Division for Economic and Social Information, 1983, p. 3). This focus on an individual's loss or lack of normalcy, or their inability to perform what is normal, is often referred to as the *medical model of disability* or sometimes as the *traditional view of disability* (Crow, 2007). This view has been criticised as focusing on impairment as the root cause of disadvantage in the lives of people with disabilities, while ignoring socially constructed oppression, disadvantages, and stigmas which have been found to be so significant in the lives of people with disabilities.

In criticising the medical model of disability, some have pointed out that wherever the ability to perform is hindered, so goes the focus of treatment (Crow, 2007). In the case of people with disabilities, the focus is on the impairment of the individual and ways to remedy that impairment with medical interventions and rehabilitation in order to lead a more normalized life (Shakespeare & Watson, 2002). The philosophical assumptions of treatments that provide the ability to lead a more normal life suggests that a normal life is more fulfilling or otherwise better than an abnormal life of physical or mental limitations. The medical model and the medicalization of people with disabilities may rest on a dichotomy of disabled vs non-disabled (Siebers, 2012). The disabled give up rights and power in order to be cured (returned to a state of non-disabled status); this power may hinge on concepts of who is able and who is not. The concept of an ideal norm also provides some difficulty when considering sexuality and sexual behaviour: some have argued that the variety of sexual behaviours exhibited by humans precludes the possibility of a sexual average or normalcy (Kinsey, Pomeroy, & Martin, 1948; Kinsey, Pomeroy, Martin, & Gebhard, 1953). And others have argued that we can learn a lot about erotic potential from those exploring uncommon sexual relations, even ones that were once considered pathological, such as BDSM relationships and same sex relationships (Kleinplatz, 2006).

The *social model of disability* is distinctly different in focus from the medical or traditional model of disability. The social model of disability shifts the view onto “disabling social, environmental and attitudinal barriers rather than lack of ability” (Crow, 2007, p. 3). This philosophy sees disability as an aspect of social oppression added on top of the individual’s impairments. The view emphasizes that society is not constructed with favourable conditions for people with disabilities and was instead designed with average or normal ability in mind. This has been instrumental in fighting for social changes that have improved the lives of people with disabilities by removing or reducing those physical barriers (Shakespeare & Watson, 2002). The social model of disability provides clear arguments for changes to society and environments to reduce barriers for people with disabilities. For example, it’s easy to see how changing a set of stairs into a ramp allows access to a building for people with disabilities; the social model challenges us to think of why a ramp was not considered during initial construction. This view was embraced as being liberating by many people with disabilities, “suddenly, people were able to understand that they weren’t at fault: society was. They didn’t need to change: society needed to change. They didn’t have to be sorry for themselves: they could be angry” (Shakespeare & Watson, 2002, p. 5).

The social model of disability and the medical model of disability provide contrasting viewpoints of how sexuality and difficult sexual issues are conceptualized (Esmail, Darry, Walter, & Knupp, 2010). From a medical view of sexuality, which has largely focused on function and reproduction, the hurdle is the ability to perform physically and some believe this creates a biased focus on the ability to perform heterosexual intercourse and medical interventions to achieve it (Dune, 2012). Although erectile functioning may be improved with a penile implant, thus achieving normalcy and sexual ability, a patient may reject the surgery

because it could mean the loss of the natural and unique functioning he does have (Guldin, 2000). From the standpoint of the social model of disability, the predominant hurdles to overcome are the physical and socio-cultural barriers that prevent sexual access for people with disabilities. Such barriers may be as simple as the design of a condom package or the need for an assistant in the bedroom to improve access.

Shifting the Focus to Issues of Access

Some advocates believe that, despite growing research and attention to the sexuality of people with disabilities, the topic of “equal access to sexual relationships and sexual activity” for people with disabilities is under represented in the discussion (Shuttleworth, Roberts, & Mona, p. 2). Advocates who are concerned with improving sexual access make it clear that their stance is not specifically to find partners for each individual with a disability, but to alter the biases of society so that people with disabilities may be seen as equally viable sexual partners next to people without disabilities. From the perspective of the social model of disability the current social stigma is a barrier which is “more disabling than the physical impairment itself” (Esmail, Darry, Walter, & Knupp, 2010, p. 1151).

Some have suggested that there is a paradigm shift occurring in the realm of access for people with disabilities (Milligan & Neufeldt, 2001). Exposure to quality information online regarding sexuality (posted by researchers, rehabilitation hospitals, service agencies, advocacy groups, and other people with disabilities) may be reducing barriers to sexual expression and experiences for people with disabilities. Further, chatrooms and forums are helping to connect people with disabilities to each other and with non-disabled people which is also increasing access. There are also examples of people with disabilities as sexual beings entering mainstream

media (in the form of movies, reality TV shows, and sympathetic news media coverage) which reach a wide audience, and sometimes publically challenge myths regarding disability and sexuality or alert viewers to common stereotypes. Some have suggested that studying the effects of this media penetration should be one of the primary goals for researchers to understand the changing sexual access of people with disabilities (Shuttleworth, Roberts, & Mona, 2002).

Some have suggested that, like homosexuality, the path forward to greater rights is by the creation of a sexual culture for people with disabilities (Siebers, 2012). The sexual citizen is thought to be a new way in which people self-identify, that our sexual expression, our rights to happiness and sexual liberation, has become considerably important to our civic identity (Weeks J. , 1998). For Siebers, a sexual culture is distinctly different from a sex life in that a typical sex life is considered primarily under the control of the person engaging in it, while many people with disabilities lack that power due to a number of social and institutional barriers. Sexual culture refers to the greater cultural representation and rights of sexual identity. Disabled sex expands the definition of normal sexual behaviour and exposes the fragile separation of public and private life.

The Reintegration of Impairment or a Renewed Social Model

At the more extreme end, social models of disability ignore difficulties due to impairment and focus only on social oppression (Shakespeare & Watson, 2002). However, more recently, theorists have considered a reintegration of impairment into the equation citing that the power of the social model was in its simplicity and that its usefulness may have become outlived. Sticking to an orthodox ideology that only society needs to change in order to solve the problems of people with disabilities sends the message that the personal experiences of pain and limitation

caused by impairment is not an important area to improve (Crow, 2007). For Crow, silence regarding the experience of living with impairments likely stems from fear of a slippery slope: admitting to impairment means undermining the positive “SuperCrip” image of campaigns, may be discouraging, may be too complex of a message, or may fuel a belief that disabled lives are not worth living (Crow, 2007, p. 4). However seductive the social model may be, we must also admit that some obstacles are not generated by the environment, for instance Shakespeare and Watson ask “how can the social environment be implicated” for an impairment which causes constant pain (Shakespeare & Watson, 2002, p. 18).

In order to move forward, some have suggested a shift toward viewing impairment not as something that some people have and others do not, but to view all people as having impairments (Shakespeare & Watson, 2002). Putting all people on a spectrum of disability may reflect certain realities of life: “No one’s body works perfectly, or consistently, or eternally.” (Shakespeare & Watson, 2002, p. 26). By sharing that spectrum of impairment, and being open to medical treatments that improve lives, we can also acknowledge that not everyone is limited by social oppression. While for Crow the interpretation of impairment can simply be changed instead, “Impairment simply means that aspects of a person's body do not function or they function with difficulty. Frequently this is taken a stage further to imply that the person's body, and ultimately the person, is inferior. However, the first is fact; the second is interpretation.” (Crow, 2007, p. 6).

Problematisation

Foucault described problematisation as the way in which a domain becomes a political issue, where political solutions/regulations play a role, but are often unable to fully solve the problem (Foucault, 1998). Problematisation is a process by which a rather unnoticed way of

being or domain of action becomes a political issue, often through challenging questions that had not previously been of a political nature. Some have described it as involving a loss of familiarity with the field, through a changing historical landscape that instigates difficulty in that area, causing reflection on our ways of existence (Vertraete, 2009). Finally, problematisation is a response to those difficulties, but the possible responses are limited to solutions in the vocabulary and syntax that the problem was formulated in. For example, if social barriers prevent people with disabilities from achieving sexual expression, then barriers must be removed or overcome in order to allow access. Taking a discursive analysis, Vertraete (2009) suggests that disability was problematised during the eighteenth century, partly in response to changing philosophical notions regarding solitude—connecting solitude, disability, and the broader assumption that masturbation is harmful to an individual.

The factual and historical nature of Vertraete's claim is well beyond the scope of this thesis; however, a great deal of interest in the sexuality of people with disabilities has recently developed that demands political attention. Additionally, it seems at least that care workers hold liberal views regarding disability and masturbation but are more concerned with sexual partnerships and limiting sexual decision making of those with disabilities (Yool, Langdon, & Garner, 2003). Furthermore, sexological research has long been driven by a variety of forces and purposes outside itself and not for some pure scientific quest for knowledge (Bullough, 1994). Bullough points out that sexual research has a long history of being used for political purposes by a wide range of groups (i.e. moralistic governments, repressed minorities, medical doctors etc) to support various agendas. For example, early research into homosexuality was spearheaded by Karl Heinrich Ulrichs, considered the first openly gay man in the modern Western world, who was actively protesting the adoption of unjust and discriminatory laws which would eventually

enter German courts (Bullough, 1994). Ulrichs set in motion the investigation of sexual orientation as a developmental and biological process, suggesting that same-sex attraction was little more than a slight variation in the typical process of sexual differentiation (which Ulrichs noted was itself a very small difference). Nearly a century later, renowned neuroscientist Simon LeVay, himself openly gay, would discover small sexually dimorphic areas of the brain, reigniting interest in the biology of sexual orientation and gender (LeVay, 1991). Bullough also cites a contemporary and friend of Ulrichs, the gay rights activist Karoly Maria Kertbeny, as being responsible for coining the terms *homosexual* and *heterosexual*, which were later popularized by Krafft-Ebbing (Bullough, 1994). The effect of the new terms was to distinguish same-sex orientations from opposite-sex orientation as well as to distinguish same-sex attraction from other disparaged and/or criminal sexual activities (bestiality, sodomy, and pederasty).

Sex Work and Facilitated Sex

Sexual surrogacy presents as a way in which governments can respond to the problematisation of access to sexual needs for people with disabilities. Some advocates have called upon governments to financially support programs that would provide the services of sexual surrogates to the disabled community (Shapiro, 2002) and increasingly access to commercialized sex in general is being considered an embodiment of sexual rights for people with disabilities (Liddiard, 2014).

In Shapiro's article, it is repeatedly affirmed to the presumably skeptical reader that sexual surrogacy is critically different than prostitution: the key difference being that surrogacy provides much needed sexual self-esteem to the person with a disability while prostitution merely provides sexual gratification (Shapiro, 2002). The professionalism of the craft and future

sexual-esteem of the client depends upon the surrogate following guidelines for activities that, although frequently described as intensely pleasurable (even more pleasurable than they would be for a person without a disability), are not done for the sake of pleasure. It's suggested that sexual surrogacy is a therapeutic process, one which assists people with disabilities in learning about their bodies through touch and supportive conversation to build sexual self-esteem (Shapiro, 2002). However, some studies of surrogates indicate that sexual surrogates do engage in sexual activity with clients, but consider it outside the realm of their job as surrogates (Limoncin, et al., 2014).

The assertion that sexual surrogacy is different from other forms of sex-work is further highlighted by researchers that confirm sexual surrogacy is a way for people with disabilities to “attain the right to explore their sexuality in a safe setting...” which can only be guaranteed “if sexual assistants are trained and carefully selected by specialised organisations.” (Limoncin, et al., 2014, p. 1). Researchers compared which sexual activities untrained and trained surrogates had provided to clients. While nearly all untrained sexual surrogates were found to provide oral sex, masturbation, or intercourse with clients, 47.5% of trained sexual surrogates claimed to only do one or more of those activities. In addition to providing greater variety and frequency of genitally focused sexual stimulation, untrained sexual surrogates were also more likely to take payment or gifts for their services and to be sexually attracted to people with disabilities (Limoncin, et al., 2014). Researchers raised concerns that untrained surrogates were in fact similar to prostitutes and feared that they may act in an exploitative manner to satisfy a sexual fetish.

A number of normative assumptions pervade the discussion and highlight the political agendas of various parties involved. For example, there is a prevailing suggestion that certain pleasurable sexual activities, when paid for, may be harmful. Those pleasurable activities are associated with prostitution to justify and differentiate sexual surrogates as professionals, thus demeaning one sex worker as non-professional and harmful in order to build the reputation of sexual surrogates. And, despite the assertion, evidence like this does nothing to support the conclusion that sexual surrogacy is helpful to attain sexual rights for people with disabilities; instead it implies sexual expertise is in the able-bodied professional to bestow upon the disabled client. Providing a solution by means of sex-workers because men with disabilities are seen as disempowered and suffering, may inadvertently further entrench the stigmatizing view of men with disabilities as disempowered and sexually incapable because they cannot find partners in a typical fashion (Eunjung, 2010). Additionally, the reasons men with disabilities claim to seek out the services of sex workers does not differ by the job title of the sex worker (Liddiard, 2014) suggesting the professional status of the sex worker has little to do with the needs or desires of the client and more to do with the political needs of the advocate.

Men with both physical and mental disabilities may seek out sex workers; however, results of those encounters may vary regarding the quality of the men's experiences (Jones, 2012). For example, some men have faced negative experiences: threats of extortion, confusion over the negotiated price, threats of violence, or payment being taken without delivery of services. Others have had positive experiences: the sex worker stayed for the appropriate amount of time, the agreed upon act went as planned, and the men experienced a sense of validation. Although the legal status of various forms of sex work varies from country to country, and provides a host of ethical concerns to those who may be involved in supporting a person with a

disability seeking those services, facilitating sexual experiences may be an area where service can be improved (Earle, 2001).

While providing funding for men to hire legalized sex workers is status quo in some countries, we are reminded that it is a rarely discussed option for women with disabilities (Baxter, 2008). Women with disabilities have typically shown little interest in paying for sexual services, as do few women without disabilities (Liddiard, 2014). Liddiard proposes that such sex differences are based on heteronormative cultural expectations that support male sexual desires but conflicts with female sexual identities.

Mark O'Brien's 1990 article *On Seeing a Sex Surrogate* was recently adapted for the screen as the Hollywood film *The Sessions*. O'Brien's original article retells his hiring of a sexual surrogate with the support of a therapist and the subsequent effects of the sexual experience on his life (O'Brien, 1990). At the end of the article O'Brien writes that, now four years after termination with the surrogate, he is disappointed in the experience, has returned to a life of social isolation in his iron lung, is hopeless at finding a romantic partner, and sees the notion of continuing to pay for sexual encounters as meaningless. However, *The Sessions* portrays a typical Hollywood ending: O'Brien almost immediately meets a new female partner after termination with the surrogate, appearing pleased (Lewin, 2012). O'Brien's article is nuanced regarding his barriers and feelings of hopeless isolation, while the film solves these issues with successful sexual coitus. Another commonly described issue of access is a lack of sexual portrayals of marginalized populations, or various body types, in mainstream media (older people, larger sized, gay, lesbian, bisexual, transgender, and people with disabilities) (Tepper,

2000). However, the theme of prostitution and the loss of male virginity is perhaps as popular in South Korea (Eunjung, 2010) as it is in North America (Liddiard, 2014).

Facilitated sex is a complicated issue, one which is fraught with moral issues for those hired as support workers (Earle, 1999). Facilitated sex is on a large continuum from very basic help such as providing sexual knowledge, up to attending social events, negotiating prices and activities with a sex worker, helping a person undress, setting up equipment, assisted masturbation, or personal assistance facilitating sex with a partner. The home of a person with a disability is also the workplace of the care giver; creating a space that requires “people with physical disabilities negotiate their sexual health without crossing professional boundaries.” (Browne & Russel, 2005, p. 375). Interviews with support workers suggests that they are more likely to assist with facilitated sexual activities when they perceived sex as a need instead of a want and the sexual activity was in line with their own sexual morality (such as sexual orientation) (Earle, 1999).

Conclusion

In order to resolve barriers to sexuality, advocates for people with disabilities continue to push for models of disability that will support the rights and needs of people with disabilities. Sexual access is considered an important goal for advocates, one which may require shifting social attitudes to accept people with disabilities as sexual citizens, allowing for non-normative sexual culture. Some advocates are developing models favouring integration of disability, increasingly taking recognition of the difficulties of impairment on the lived experience of people with disabilities rather than focusing solely on social factors. The topic of sexual surrogacy, along with Foucault’s notion of problematisation, shows how approaches to solutions

may be limited by the discourses these issues were formed in. Those solutions may be limited in the kinds of help being provided and highlights the complicated nature of overcoming barriers.

CHAPTER III SEXUAL IDENTITY

Sexual identity may be conceptualized as an ongoing process of development throughout the lifespan concerning the formation and incorporation of sexual values, behaviours, and desires, as well as sexual orientation (Worthington, Savoy, Dillon, & Vernaglia, 2002). Sexual identity, as a whole, is thought to involve change and development over time, reflecting a person's cultural and social climate (in particular values and beliefs regarding sexual behaviour and morality) as well as the person's active role in exploration and commitment to an identity (Morgan, 2012). Research into the effects of disability on sexual identity can be summarized as largely negative, adding significant difficulty to adjustment and/or development, risk, and deviation from statistical norms and milestones as well as social isolation and exclusion from sexual education and sexual experience (Kewman, Warschausky, Engel, & Warzak, 1997). Additionally, many advocates cite that a significant barrier to the development of sexual identity is the stereotype that people with disabilities do not have sexual feelings, that they are asexual (Milligan & Neufeldt, 2001). In order to work against the sexual discrimination/repression faced by people with disabilities, some advocates propose the creation of a distinct sexual culture for disabled people (Siebers, 2012) and the production of sexually positive media about disability and sexuality in order to influence change (Shuttleworth, Roberts, & Mona, 2002).

Sexual Identity and Sexual Orientation

Sexual orientation, which is sometimes confused with sexual identity, refers primarily to sexual attraction to the sex and gender expression of another person; an attraction that is unlikely to change (APA Task Force on Appropriate Therapeutic Responses to Sexual Orientation, 2009). Research into the development of sexual identity has often focused specifically on sexual

orientation groupings such as lesbians, gay men, bisexuals, and heterosexuals—a practice which some have challenged as being constrained to a gay-straight dichotomy of sexual orientation, thus hindering sexual identity theory and research through methodological limitations (Dillon, Worthington, & Moradi, 2011). Interestingly, some have proposed that heterosexual identity may have been a neglected topic when it comes to the study of sexual identity development, suggesting that the conceptualization of heterosexual identity as “uniform and unremarkable” may be mistaken (Morgan, 2012, p. 79). Morgan further elaborates that, although models and research of gay and lesbian sexual identity formations are more common, they may also be limited by inaccurate assumptions of a linear process involving coming to terms with homoerotic desires and subsequent changes to self-concept (changes which lead to acceptance, actions, internalization, and disclosure to others).

Consistent with that notion, gay, lesbian, and bisexual youths have been found to have a varied tapestry of factors influencing sexual identity formation which may be linked with consistency of sexual orientation over time (Rosario, Schrimshaw, Hunter, & Braun, 2006). Most importantly, family acceptance has been found to be significantly important to the health outcomes for LGBT teens (such as self-esteem, social support, general health, and protective factors against depression, substance abuse, and suicide attempts/ideation) (Ryan, Russell, Huebner, Diaz, & Sanchez, 2010). Conflicts between sexual identity and sexual orientation are difficult, often forcing people to choose between sexual urges and personally important social, cultural, and religious values regarding gender roles, sexual identity, and sexual behaviours (APA Task Force on Appropriate Therapeutic Responses to Sexual Orientation, 2009). It must be acknowledged that disability may be intricately involved in various forms of sexual identity

and sexual orientation and LGBTQ individuals with disabilities may face even more restrictive living situations than their heterosexual counterparts (Noonan & Gomez, 2011).

Although, in some countries, there is a general trend towards greater acceptance of LGBT orientation, researchers suggest that many people become ambivalent with regard to LGBT rights due to a conflict between core values regarding sexual orientation as a biological imperative coming into conflict with political and/or religious institutions of which they are members (Craig, Martinez, Kane, & Gainous, 2005). Furthermore, far from being a polarized topic of liberal views against conservative ones, the views of ordinary people are made up of a textured middle ground where both positive and negative views vary across multiple angles of the topic. For example, people may have mixed opinions on the topic such as seeing homosexuality as perfectly natural and acceptable behaviour, but gay marriage as unacceptable due to adherence to a religiously informed view.

Variations within sexual identity, sexual orientation, and gender too have been linked more directly with disability as effects related to the genetic or epigenetic factors. For example, Baron-Cohen's "extreme male brain theory of autism" posits that stereotypical features of autism such as a strong interest in systems and low ability to empathize represents a high degree of masculinization of brain regions related to those abilities (Baron-Cohen, 2002, p. 248). Baron-Cohen cites numerous studies which show that in the general population men score slightly higher on scores relating to understanding systems while women score higher on emotional intelligence. Questionnaires that assess these traits show that for both males and females with autism, scores reflect an extreme end of a typical male response pattern, though a small sex

difference still remains between men and women with autism on those traits in typically sexed patterns (Baron-Cohen, et al., 2014).

Congenital adrenal hyperplasia (CAH), a development disorder which increases androgen release prenatally, is another example of a disorder which is thought to masculinize behaviour and gender expression in women (Pasterski, et al., 2007). Findings suggest these masculinizing effects on certain traits may influence women with CAH to be more aggressive and active as youths (Pasterski, et al., 2007), have increased spatial abilities (Barenbaum, Korman Bryk, & Beltz, 2012), increased preference for a career over having and raising children (Dittmann, et al., 1990), and an increased interest in same-sex sexual relationships with other women (Dittmann, Kappes, & Kappes, 1992). While girls with CAH might be predicted to develop issues regarding gender identity (i.e. a desire to identify as male rather than female) due to the prenatal influence of androgens in the brain, studies actually show that females with CAH predominantly identify as women and girls with little to no discomfort (Barenbaum & Bailey, 2003). Interestingly, there is some evidence from studies regarding sexual self-esteem which suggests that adherence to masculine gender norms is more beneficial and important to all sexes and orientations outside of heterosexual women (Amos & McCabe, 2015).

Some have criticized the above evidence for a biological influence on gender and sexuality where the brain is suggested to become organized along gendered paths during fetal development, suggesting instead that researchers have overlooked competing explanations (Jordan-Young, 2012). For example, Jordan-Young suggests that factors like steroid disruption during early development, intensive medical interventions and surveillance, the shaping effects

of genital morphology, and the expectations held by others are what shapes the sexual orientation and gender expression of women with CAH.

Transgender, Intersex, and the Medical Model

One cannot proceed without discussing the issues raised in the realm of trans and intersex identity within the context of the medical system for the similarities with disability issues. In the case of a transsexual identity one must be declared as having a disability by a professional in order to receive access to the desired surgery to achieve satisfactory embodiment; transsexualism under the medical model is a pathology with significant legal, medical, and normative barriers (Spade, 2003). While, on the other hand, a baby deemed intersex for having too small or too different of a penis may be reassigned as a female or provided surgery to improve the look and size of the penis regardless of the outcome to the sensitivity of the genitals in the process—thus creating a disabled organ (Wilkerson, 2012). The essentialism of a person's sexual identity and gender that was of great importance in deciding access to surgery for a trans person is disregarded for a purely social constructionist and surgical approach to manufacturing a body and identity for a person deemed intersex to suit a medical professional. Wilkerson further points out the immense double standard: to trim a clitoris for being too big is considered a preferable intervention on the basis of normative beauty standards, yet clitoradectomy for religious reasons is barbaric. And, the medicalization of such beauty standards, confirms the standard while removing the autonomy of the individual to choose as well as limiting the opportunity for society to accept a diversity of bodies. It must also be acknowledged that this thesis follows a similar pattern: the sexuality of people with disabilities is first declared significantly impaired with a

literature review of their sexual problems before considering ways of helping them achieve sexual success.

A Sexual Identity for Disabled People

As previously stated, some advocates have urged for the creation of a distinct sexual identity for people with disabilities on a political basis (Siebers, 2012), as well as the creation of accompanying media to encourage that sexual identity/culture and sexual access (Shuttleworth, Roberts, & Mona, 2002). The necessity of such media and identity can be related to the notion that the sexual development of people with disabilities challenges typical societal norms and expectations regarding sexuality and gender (Shakespeare, 1999) and that media plays a significant role in sexual identity (Dune, 2012). Furthermore, the typical negative assumptions regarding the sexuality of people with disabilities, has also been proposed to be internalised causing negative sexual identities (Di Giulio, 2003). However, a great difficulty is readily observed in the creation of a distinct sexual identity for people with disabilities: many people with disabilities do not wish to identify personally or politically as disabled (Shakespeare & Watson, 2002). 'Disabled' may or may not be a part of the sexual or self-identity of a person with a disability; instead many may focus on wanting to be normal or other aspects of their identity such as culture, gender roles, or sexual orientation. At the same time, many people with disabilities do state that they want more information regarding their disability and sexuality (Poisson & Mathgen, 1977) as well as wondering how to feel sexy (Kaufman, Silverberg, & Odette, 2007). Resources and media that highlight or aim to improve the sexual identities of people with disabilities have begun to proliferate and some have suggested that studying these

positive representations and their complex effects on access and exclusion is of utmost importance for researchers (Shuttleworth, Roberts, & Mona, 2002).

Sexual guide books may be one of the most obvious and direct forms of intentional assistance for the improvement of sexual identity. Therefore, it must be considered a positive for disabled sex to be represented in the massive mainstream tome *Guide to Getting it on* by Paul Joannides (2013). The book includes chapters for sex with a disability, diabetes, and sexually specific cancers, briefly tackle issues like loss of spontaneity, body image, performance fears, developmental disabilities, acquired disabilities, erection and lubrication with spinal injury and many other relevant topics. Although the chapter is written from a tone that implies the reader is without a disability (for example, Joannides asks the reader to consider that they probably have not in fact considered a person in a wheelchair to be just as sexual as they are themselves) it may provide useful information and promote the sexual identity of people with disabilities to the public.

What could be learned from examining the sex lives of people with disabilities from the perspective that they have valuable lessons for each other and can be guides unto themselves? The authors of *The Ultimate Guide to Sex and Disability* attempt to answer that question by mixing the available research information on sex and disability, the professional and personal experiences of the authors, and survey responses from people with various disabilities regarding their sexual experiences (Kaufman, Silverberg, & Odette, 2007). Using the survey responses, the authors highlight many sexual topics with personal narratives and examples from people with disabilities. With the exception of a chapter challenging myths regarding sex and disability, the various chapter topics are typical of a sexual guide book: sexual health information, oral sex and

masturbation, yoga and tantric sex, sexual desire and self-esteem, sex toys, S/M, penetration and positioning, etc. The authors often make inclusive statements and present options/alternatives for those unable to participate in certain activities due to issues of disability (mobility issues, chronic pain, fatigue, etc).

Further exploring the sexual potential of people with disabilities is *Power Exchange Books: Playing with Disabilities*. This book explores various topics related to the practice of BDSM with a disability by using personal narratives and exposition provided by BDSM community members with disabilities. A chapter by Seagraves (2007) describes her experience and needs as a Deaf women exploring both submission and domination with various partners. Seagraves uses the playful tagline, “I can’t hear you crying” with her partners—emphasizing an exaggeration of both her impairment and sexual character as a dominant (Seagraves, 2007, p. 19). Another woman, writing under the pen name “slave m,” describes how giving all of herself, including her Lupus, to her master made her illness, career, family, and life more manageable (slave m, 2007). For example, she states that “I can’t properly serve Him if I haven’t taken care of my own physical needs first” (slave m, 2007, p. 54). She emphasizes the need for open and honest communication of her current health status to her partner in order to engage safely with her sexual identity and describes how the rules of their sexual roles enhances her monitoring of her illness in a healthy way.

Pleasure Able: Sexual Device Manual for Persons with Disabilities is a brochure-like overview of various sex toys suggested as potentially useful and pleasurable for each of a variety of physical limitations developed by rehabilitation and disability experts in tandem with a sexual medicine expert (Naphtali, MacHattie, Elliott, & Krassloukov, 2009). The guide offers practical

advice on hygienic use and cleaning of sex toys, safety information, and detailed anatomical drawings—all paired with a brief catalogue of available sex toys, pictures, and product description. Products listed include a variety of vibrators, strapon harnesses, foam block and stool devices for positioning the body, slings, and cuffs to hold devices and hands-free options. Some people with physical disabilities express hope that technological advancements in sex toys will allow them greater sexual experiences (Browne & Russel, 2005).

Sexual Education

Sexual education has been considered a significant issue for people with disabilities, findings indicate that youths with significant physical disabilities may be left out of sexual health talks and that youth with developmental disabilities may receive little or no sexual health information, although this is improving as societal attitudes change (Di Giulio, 2003). However a pilot study explored the usefulness of sexual health websites to improve access to sexual health information for young women with physical disabilities and found that it was a significant success (Pendergrass, Nosek, & Holcomb, 2001). A lack of sexual knowledge has been identified as a strong component in unsafe sexual practices and sexual victimization among people with disabilities (Brown-Lavoie, Viecili, & Weiss, 2014) and so improved access to knowledge is likely to have wide effects. Perhaps more important than their main finding was the demographic information provided and their own analysis of what it signified: the sample was significantly Caucasian as well as considerably educated and affluent (Pendergrass, Nosek, & Holcomb, 2001). Despite the fact that a growing number of households will have obtained Internet access since the time of the study, it may be that a significant difference in access will

appear between people with disabilities dependent upon their financial, residential, and racial status, as well as the specific limitations of their impairment.

In both men and women actual knowledge, facts regarding safe sexual practices, are an important factor in safe sexual behaviour such as condom use (Ryan, Franzetta, & Manlove, 2007). Condom use by men has also been linked to how much sexual knowledge a man perceives that he has: the more sexual knowledge a man believes he has, the more likely he is to use a condom. However, both sexes with autism are more influenced by actual knowledge (Brown-Lavoie, Vecili, & Weiss, 2014) which highlights that some may need “comprehensive and personalized curricula that directly teach what is often learned incidentally or naturally by other individuals” (Gougeon, 2010, p. 330). For example, early interventions have been shown to be exceedingly effective in helping children with autism to develop an understanding of the mental states of others and respond with appropriate emotional responses (Baron-Cohen, Golan, & Ashwin, 2009). These effects were garnered through the creation of video tapes designed for children with autism that feature emotionally expressive trains (the content chosen to take advantage of the greater interest in systems). This suggests that, at least in some cases, it may be pertinent to develop sexual education media that matches specific learning difficulties related to disabilities.

Erotic Potentials

It has been argued that we can learn a lot about human erotic potential from those exploring uncommon sexual relations, such as BDSM and homosexuality, which can then enhance erotic potential in other people (Kleinplatz, 2006). The full and detailed list of lessons described by Kleinplatz is too long to summarize here, however, they emphasize self and other

exploration, vulnerability, sharing, deep communication, meaning, creating heightened arousal, trust, multi-purpose sex, transcendent or spiritual sex, transformation and healing, aiming for incredible rather than mediocre, and taking risk. However, it may be similarly interesting to learn from people with disabilities, particularly regarding eroticism, self-care, the integration of disability into sexual play.

Some authors have highlighted the promising stories of resilience, resistance, and coping skills related to positive sexual identities and meaning among people with disabilities. Interview responses from people with motor impairments (Spina Bifida, Spinal Muscular Atrophy, and spinal cord injuries) reflected a resistance to, but not a rejection of, dominant Western cultural values regarding sex and sexuality (Guldin, 2000). Particularly highlighted was a view that orgasm is not genitally centered, that there are orgasms in the shoulder, lips, and mouth as well as “heart-orgasms, mental orgasms, and full-body-creativity-inspiring orgasms” (Guldin, 2000, p. 235). Body image was another focus of meaning and resistance identified in the research. Although there was not a rejection of beauty standards, there was some compensatory view that something about their mind or body was sexy: a sexy body part, their total person was sexy, a sexy personality, sexy emotions, and/or a strong belief that they are a sexual being. Some men with disabilities felt they had developed the skills to become better lovers than men without disabilities, paradoxically they felt that they developed these skills because of their disability. They expressed a sense that men without disabilities were in fact the ones who were sexually disabled by their lack of skill and sexual introspection. Another young woman in the study found sexual empowerment with the term “slut” by acting against the expectations of society and her parents that she ought to be asexual.

Autism presents a potentially more complicated picture of sex and desire than other disabilities (Groner, 2012). For example, Groner relates the story of Dawn Prince-Hughs, a lesbian female exotic dancer with autism, who studied the rules of sex from pornography, erotic literature, magazines, and from friends to form a guide for her behaviour. When she implemented those rules into a pattern, each sexual encounter was followed by immediate plans to cohabit with the woman she had seduced. Prince-Hughs eventually reaches a greater understanding of neurotypical love by observing her own connection with gorillas. Groner also tells the story of Danny Jacobs, a man with autism who went about casual sex with many female partners as a robotic task, not socially or sexually rewarding. Upon marrying his wife, Danny no longer engaged in his task-oriented accomplishment of sexual routines, revealing himself as sexually passive and uninterested.

What must be made explicit is the right of people with disabilities to also develop asexual identities. Both research into autism and the narratives of some people with autism expose a complicated sexuality and, in some cases, sensory and social impairments which may discourage sexual activity (Groner, 2012). Although researchers have worked to show that sexuality is important in the lives of people with disabilities such as autism (Lawson, 2005) it must also be respected that they have a choice in developing that sexuality to their liking. Perhaps more difficult to moderate is the desire to help those who may have been misinformed or harmed rather than those who we may write off as having a medical reason for their disinterest in sex. For example, a number of women with intellectual disabilities may avoid sex after developing negative perceptions such as a fear of the first sexual act, fear of negative consequences, physiological concerns and a perceived or actual lack of pleasure (Bernert & Ogletree, 2013).

The Internet

Internet access has caused therapists and researchers to wonder at the variety of effects it has on sexuality (Weeks, Gambescia, & Hertlien, 2009) and some have suggested that there is a paradigm shift occurring in the realm of sexual access for people with disabilities due to exposure to quality information online regarding sexuality as well as communication through chatrooms, email, forums, and social media (Milligan & Neufeldt, 2001). Many people with physical disabilities report using the Internet for accessing sexual health resources and the effectiveness of that exploration has previously been identified (Browne & Russel, 2005). Websites, such as the one provided by the Kinsey Institute (www.kinseyinstitute.org), provide accurate and diverse articles on a number of sexuality and sexual health topics, including a section devoted to disabilities.

The Internet has also provided a platform for personal narratives as well as articles and videos to circulate more freely and to reach more readers. For example, articles about an upcoming accessible orgy can spread rapidly through news sites, advertising the x-rated event and the sexuality of people with disabilities (Strobel, 2015). The event is set to serve the disabled community with space for wheelchairs, hydraulic lifts, and a sign language interpreters for the deaf; and while tickets cost money, support workers can attend free of charge. An article written by Shane Burcaw (2015), a young man who uses a wheelchair, has also been widely circulated by various Internet news sites and on social media. In the article he focused on his experiences of strangers asking him if his able-bodied girlfriend is his sister, caregiver, or nurse. He and his girlfriend allegedly brush these questions off with humorous and sarcastic replies. But Burcaw also states that he believes a relationship between a person with a disability and an able-bodied

person can be deeper in closeness than other relationships by teaching your partner how to care for you. This highlights two interesting points which are reversals of what is expected from previous research: a feeling that having a disability leads to an actual advantage in relationships and that taking on a care giving role can increase closeness rather than signal doom for a relationship.

A disability awareness consultant, Andrew Morrison-Gurza (2015), provides his experience as a gay man with cerebral palsy. Morrison-Gurza describes his unique body as a source of sexual capital, a pleasure that his partners cannot get somewhere else, a body which goes against the idealized image of young gay men as athletic, good-looking, and with a toned chest. In another piece written for *The Advocate* he described the excitement of using the Internet to invite another man over for a sexual encounter, highlighting both the sensual nature of sex and the freeing aspect being able to be sexual (Morrison-Gurza, 2014). Disability is described as an integrated and valued part of his person during the sexual act, rather than something he must exclude; he only feels challenged when the moment comes that he must ask for help dressing after sex. Living examples of such positive aspects of disabled sexuality may inspire other men with significant impairments (Tepper, 1997).

One cannot overlook the more interactive elements of the Internet when it comes to disability and sexuality. For example, the popular social media website Reddit (www.Reddit.com) features several forums (called *subreddits*) devoted to disability and sexuality. These discussions range from communities devoted to sexual advice and information, to helping people find romantic partners. AbleHere (www.ablehere.com) and other websites also include a category for sexual discussions. Websites like these that involve people with

disabilities as active participants in developing sexual identities of their own and with others cannot be overlooked as an interesting and positive development.

Women with disabilities have voiced concerns that many face objectifying sexual invitations from strangers because of their disabilities in email or other social media (Kafer, 2012). Regarded as a paraphilia in the *Diagnostic and Statistical Manual of Mental Disorders*, devoteeism is an attraction to disabilities, usually those with amputations or in wheelchairs (American Psychiatric Association, 2013). This in itself does not qualify as a disorder unless the paraphilia causes distress, impairment, harm, or risk of harm to others. Research into devoteeism suggests specific individuals find specific disabilities highly arousing, often focused on one specific disability (Aguilera, 2000). An analysis of devotee discourse suggests that attraction to amputees revolves around desire and disgust, that is to say “the site of an amputation can never be neutral: it is always the determining aesthetic factor of an amputee.” (Kafer, 2012, p. 336). Kafer points out that, for some, the narrow and objectifying language may be significantly rejecting, however, many women with disabilities also find devotee communities liberating and empowering for that sexual objectification. While devoteeism is not a new phenomenon, given the increasing access for people with disabilities and social connections facilitated by the Internet, new difficulties and conversations are developing. Interestingly, some of those conversations are directed at male devotees instructing them to improve their treatment of women with disabilities on social media platforms (Stephens, 2013). Stephens, for example, states that some devotees have used deception to befriend her online by posing as other women with disabilities, or that some devotees make requests that she further alter her body with new amputations to fit their particular sexual desires.

Overwhelming Positivity

In constructing a view of sexual identity for disabled people it is all too tempting to objectify people with disabilities in two ways: as objects of inspiration and/or as sexual objects. Advocates have pointed out the clear objections to medicalization which reduced people with disabilities to their impairments, yet the imposition of a disabled sexual identity onto people with disabilities is also a form of objectification: it would be a similar injustice to force an identity of disability onto a person with a disability who wishes to identify differently (Shakespeare & Watson, 2002). Some have suggested that the ways in which people with disabilities do act with autonomy to produce a sexual identity have not been acknowledged or have otherwise been restrained by society (Sakellariou, 2012). They suggest that “care practices have often been disempowering and controlling, constructing disabled people as objects of care and locating them in the place of a passive receiver and as a burden” (Sakellariou, 2012, p. 191). Individual ways of identifying, even asexually and as non-disabled, must be respected. Additionally, the positive examples of people with disability as sexual champions overcoming adversity to become role models may be a great counter to the myths of asexuality and sexual inability; however, they also border on sexual objectification and the use of people with disabilities as objects of inspiration.

That being said, the current efforts to create a distinct sexual identity for people with disabilities may indeed be helpful, and the current developments around the internet may increase autonomy and access to partners and information. Tough questions and tougher problems may remain long after a disabled sexual identity/culture is created. For example, in what way is a sexual identity relevant to a person whose disability means that they do not

develop a concept of self? What good is a significantly positive sexual identity without a partner or the means to facilitate sex with a partner? What about disabilities that put others at risk for sexual harm? What ethical responsibilities do people who provide care for people with disabilities have regarding sexuality?

Conclusion

A variety of media has been created around disability and sexuality with the purpose of providing help to those with disabilities to develop a sexual identity. Sexual guides and other resources are adding to the discourse of sex and disability and providing helpful information to expand the choices of people with disabilities. Similarly, the Internet has opened up new spaces for sexual identity and community, as well as active participation in the development of those resources. Although many people with disabilities may not identify as disabled, research into the effectiveness of sources that are proliferating around the sexual identity of disability is necessary. Access to these technologies and media may still be influenced by affluence, ability, and privacy, and thus access and sexual identity are intimately linked. Perceiving diversity, and multiplicity, in the concept of sexual identity of all individuals may be a similarly important concept as perceiving all people as disabled and on a spectrum of disability.

CHAPTER IV ETHICS AND DISABLED SEXUALITY

People with disabilities and advocates, as well as governments and public organizations, have made considerable pledges and declarations regarding the rights of people with disabilities toward greater sexual autonomy, sexual development, and sexual expression (Caruso, et al., 1997). However, various institutional, legal, and public morality issues persist which limit those rights (Fiduccia, 2000). The sexual agency of people with disabilities is, for both historical and current reasons, a public interest (Abramson, Parker, & Weisberg, 1988). The past century witnessed the rise and fall of public and political support of the deeply disturbing eugenics movement which, among other things, resulted in significant harm to the sexual lives of people with disabilities (Munger, Gill, Ormond, & Kirschner, 2007). High rates of sexual abuse provide considerable concern for protecting people with disabilities from sexual harm while also creating fear that sexual autonomy becomes a casualty in the mandate to provide that protection (Benedet & Grant, 2007). New ways of establishing capacity to consent to sexual activity seem to provide a way to reduce institutional obligations to facilitate sexual expression rather than facilitate that development (Kennedy, 2003).

Public Morality and the Sexual Rights of People with Intellectual Disabilities

According to Abramson, Parker, and Weisberg (1988),

“public morality is relevant to the sexual restrictions often placed upon mentally retarded individuals. Despite the objective to eliminate sexual abuse, there is an extraordinary history of legislation and institutional policy designed to nullify sexual expression among mentally retarded people” (Abramson, Parker, & Weisberg, p. 329).

People with various degrees and forms of intellectual disability have faced active discrimination from marriage to procreation, as well as suffered myths that paint them as sexually dangerous and more likely to commit sexual crimes (thus a need to police their sexual behaviour) (Kaeser, 1992). Some have stated that such views were judicially condoned before the 1960's, shown throughout legal statutes which gave legal rights to the state to sterilize people with intellectual disabilities, ostensibly in order to protect society (Abramson, Parker, & Weisberg, 1988).

The eugenics movement of the 1900's grew support for institutional policies which sterilized people with disabilities (among others, most notably Aboriginals) to prevent procreation and passing on potential genetic diseases (Munger, Gill, Ormond, & Kirschner, 2007). Power and control are significant issues with regards to the politics of fertility management: governments become the gatekeepers of fertility, not only deciding what is legal and illegal, but also deciding whom is worthy of fertility (van Heeswijk, 1994). The industrial revolution and increased immigration brought an increase in poverty and criminality in major city centres, these problems were seen as caused by the "feeble-minded" and tied to concepts of racial superiority and social class (1994, p. 8). It was therefore considered by some that eugenics was a solution to multiple perceived social issues (such as the cost to the state of caring for individuals with mental illness or low IQ) which could be solved by reducing the fecundity of those considered unworthy of procreation. For example, British Columbia, Canada, enacted "An Act Respecting Sexual Sterilization" on April 1, 1933 which empowered those presiding over patients residing in Essondale (presently the Riverview Psychiatric Institution) and the Boys' or Girls' Industrial Schools (for children deemed delinquent) to submit patients to be considered for sterilization.

The act was repealed 40 years later, in 1973, as the understanding of heredity changed and evidence from the few institutions which employed sterilization showed that the Act was being used to solve behavioural problems rather than those related to heredity (van Heeswijk, 1994). By 1999 over 800 people with disabilities in Canada had won lawsuits against the Canadian government for what has been termed “wrongful sterilization” (Fiduccia, 2000). Damages from those lawsuits have resulted in settlements amounting to over \$140,000,000. The majority of those sterilized had been institutionalized in the Provincial Training School for people with developmental disabilities in Alberta, Canada. But despite those successful lawsuits and tighter legislation that has drastically reduced the overall number of sterilization procedures, some suggest that sterilization procedures may be hidden by loopholes in medical reporting systems and/or achieved as the desired by-products of other surgeries sought by parents or guardians and provided by willing doctors (Hamilton, 2012).

Recently there has been an increase in scientific findings related to the genetic correlates of mental illnesses, causing some to fear a rekindling of the eugenics movement (Munger, Gill, Ormond, & Kirschner, 2007). For example, one major project to understand the origins of mental illness suggests a genetic connection between autism, ADHD, bipolar disorder, major depression, and schizophrenia to a single gene related to the flow of calcium into neurons (Smoller, et al., 2013). However, the researchers involved in the project are clear that many more genes and other factors are also involved in the development of those disorders. Interestingly, only about 15% of all diagnoses of intellectual disabilities are related to genetic inheritance (Abramson, Parker, & Weisberg, 1988), while new research suggests a much greater importance in the random mutation of genes at the stage of sperm and ova (Vissers, et al., 2010). Such discoveries show the relative weakness of the eugenics movement and the pointlessness of the

resulting discrimination, but also the wealth of data stored in genes. This suggests that the advancements of the human genome project may be a double-edged sword: in correcting the mistakes of past falsehoods, it has also provided new knowledge which can be used to detect genetic disabilities *in utero* and thus the possibilities of selective abortions based on the genetic profile of the developing fetus (Munger, Gill, Ormond, & Kirschner, 2007).

Those opposed to the practice of prenatal screening and selective abortion suggest this again returns to a discriminatory medical model of practice which targets the disability as the problem needing treatment, is based upon stereotyping children with disabilities as burdensome to parents, and relies on misinformation regarding the quality of life a child with a disability is likely to have (Munger, Gill, Ormond, & Kirschner, 2007). Data regarding abortion following prenatal screening that found genetic indicators for down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes suggest that many parents choose to terminate pregnancies, with rates ranging between 50% and 90% (Mansfield, Hopfer, & Marteau, 1999). Asch (2003) suggests that concerns are based on two broad claims: abortion following prenatal testing is morally problematic and that it is driven by misinformation. Some express concerns that reducing the population of people with disabilities through selective abortion will also reduce their demographic political leverage leading to truncated advocacy and related fallout such as a lower quality of life (Gonter, 2004). Despite this potential political reality, many see this as an issue where the parental right to an abortion takes precedents over the political leverage of people with disabilities, often noting that abortion is chosen for a wide range of reasons (such as poverty) which supercede the feelings of people currently living with disabilities (Gonter, 2004). Concern that the political effort to accommodate people with

disabilities may decline significantly should prenatal screening and selective abortion become wide spread is relatively sound and should be taken seriously to avoid further discrimination.

The issue of inappropriate masturbation has become considerably important to parents, educators, and clinicians that are involved with children with developmental disabilities (Griffiths & Lunsky, 2000). A review of empirical case studies from the late 1960's to 2000 regarding efforts to curtail "inappropriate masturbation" suggests that, although there is improvement in ethical treatment, more work is needed and ethical questions surrounding sexual agency still remain unanswered (Tarnai, 2006). While largely focused on reducing incidents of public and self-harming masturbation, as well as promoting private masturbation, Tarnai notes that, "[o]vertolerance is not an attitude that serves normalization of lifestyles of persons with cognitive disabilities in society, in the community" (Tarnai, 2006, p. 165). Caregivers face the difficulty of accidentally promoting inappropriate behaviour by tolerating it which may enforce stereotypes that people with disabilities are sexual deviants while they struggle to positively support the sexual development of those in their care. While some of the most extreme solutions undertaken to curb masturbation have involved chemical sterilization or surgical procedures such as orchidectomy (Carlson, Taylor, & Wilson, 2000). Tarnai suggests that ultimately there is a slow evolution towards more ethical methods of behavioural change that involve simply providing knowledge or rewards to shape appropriate behaviour, methods that are successful in most cases, rather than resorting to punishment or extreme castration methods (Tarnai, 2006).

Increased Risk of Sexual Violence

Researchers have found that young women in high school with physical disabilities (or other long-term health problems) are twice as likely as non-disabled peers to experience forced

sexual intercourse (19.6% vs 9.4%) (Alrisko-Schmidt, Armour, & Thibadeau, 2010). An astonishing number of other factors correlated with sexual violence against young women such as the use of a variety of substances, feelings of sadness or hopelessness, experiences of bullying, and racial identity suggesting intersectional issues may put some people with disabilities at higher risk of sexual violence. While any type of disability increases the risk of sexual violence, intellectual disabilities, communication disorders, and behaviour disorders put the person in the highest risk category; having multiple disorders increases the risk further (Sullivan & Knutson, 1994). Some suggest that 49% of people with intellectual disabilities will have 10 or more experiences of sexual violence in their lifetimes (Sobsey & Doe, 1991). While it's more common for women to experience sexual violence than men, men with disabilities are twice as likely as other men to experience sexual violence (The Roeher Institute, 1995).

Capacity for Consent to Sexual Activity

Some have proposed that legal issues of consent for people with disabilities become troubled due to a tension between the competing desires to protect people with disabilities and simultaneously promote their sexual autonomy (Benedet & Grant, 2007). Of particular importance regarding issues of consent and intellectual disability is sexual assault, in particular, as stated women with mental disabilities face high rates of sexual assault and thus there is a strong desire to provide legal protection. Determining the competency of a victim of a sexually related crime is seen as a necessity in order to establish legal charges against the accused and protect people with disabilities from harm, thus, there is a significant focus on those with intellectual disabilities (Kennedy, 2003). As expressed above: there is a struggling disparity

between the rights of people with disabilities and the continuation of boundaries and limitations placed on their autonomy (Wilson, Parmenter, Stancliffe, & Shuttleworth, 2011).

People with intellectual disabilities may be seen as unsuitable partners because their disability implies an inability to consent to sexual activity (Milligan & Neufeldt, 2001). Caregivers have concerns regarding liability (Noonan & Gomez, 2011), as well as fears of sexual abuse, and fear of sexual consequences such as pregnancy and sexually transmitted infections (Eastgate, 2005). The issue of consent to sexual activity often revolves around cognitive impairment and therefore, capacity to consent to sexual activity with another person may pose as a type of intellectual barrier which some may not be considered able to overcome (Noonan & Gomez, 2011). Some suggest that consent to sexual contact requires knowledge, understanding, and voluntariness (Stavis & Walker-Hirsch, 1999) and that some people with intellectual disabilities will never meet those criteria in full (Dukes & McGuire, 2009). Dukes and McGuire further suggest that consent may be a matter of degrees where consent to some activities may be acceptable and some not, that capacity to consent may fluctuate depending on psychological state and can increase via specifically tailored sex education.

Capacity to consent of individuals with intellectual disabilities is becoming a matter of psychological testing, such as the Sexual Consent and Education Assessment (SCEA), which means to ease the burden felt by institutions (Kennedy, 1999). The SCEA evaluates an individual's ability to consent through question regarding their sexual knowledge, safety practice, and inappropriate sexual behaviour with the help of someone that knows the individual well (ie a caregiver or parent). These questions include knowledge about body parts (from very basic to more complex) and questions that meet the minimum standards of sexual consent and

consequences of sexual activity. Similar tests have been developed from Kennedy's scale for testing those with bipolar disorder and schizophrenia, finding that those with severe disorders may not be able to provide consent (Mandarelli, et al., 2012). Manderelli et al. further suggest that regardless of severity of the disorder, patients were at risk for sexual consent incapacity.

However, current methods used to measure capacity to consent which test for IQ, functional behaviour, and sexual education, have been shown to be inferior to neuropsychological testing of executive functioning (i.e. a tower task, card sorting, and word fluency) (Kennedy, 2000). Executive functioning is an umbrella term for multiple sub-processes thought to be highly dependent on (but not exclusive to) the frontal lobes of the brain (Elliot, 2003). These processes contribute to goal directed behaviour, modification of behaviour in light of new information, planning and decision-making, organization, and behavioural inhibition. This line of investigation is suggestive of a future where capacity to consent is, at least partially, a question of health and integrity in certain areas of the brain.

While there appears to be sound reasoning to consider the potential usefulness of such tests, consideration must be made for the precedent being set: a test score on a game or language test may disenfranchise a person from consensual, desired, and safe sexual practices. Testing as a means to restrict sexual exploration and autonomy appears to run counter to goals identified by advocates regarding maximum growth of sexuality within a person's limitations. Testing for capacity to consent appears to remove the burden of institutions from having to facilitate the sexuality of those in their care. These groups have expressed the greatest need for support (McCabe, 1999).

While support for sexual activity and development is growing, the translation into reality appears to some to be restricted by inadequate frameworks to provide proactive support for the sexual expression of people with disabilities (Hamilton, 2009). Care workers have been found to support the sexual rights of people with disabilities; however, they also describe significant discomfort with the real-life sexual relationships of persons in their care, particularly around the issue of possible pregnancy and parenthood that could result from those relationships (Eastgate, Scheermeyer, van Driel, & Lennox, 2012). They too consider the question of capacity to consent as a concern (Caruso, et al., 1997). Care workers suggested a need for sexual education for those in their care, but that such education was not enough and that persons with intellectual disabilities would benefit from ongoing support for sexual issues.

Biases regarding age, gender, and intellectual disability may influence who is perceived as capable of giving consent to sexual activity. For example, younger adults expressed lower acceptance and more doubt for the capacity to consent of older women, especially when they were described as cognitively impaired (Allen, Petro, & Phillips, 2009). Interestingly knowledge of aging and sexuality was not found to influence those judgements, however, personal attitudes of late-life sexuality held by younger adults predicted views regarding acceptance of sexual expression and capacity to consent of older women. Additionally of interest: negative attitudes and stereotypes held by younger generations regarding sexually active older women have been found to inhibit the sexual expression of older women. Similar studies have shown that some care workers hold very liberal attitudes towards masturbation, but hold less liberal attitudes regarding sexual intercourse, homosexual relationships, and the involvement of people with disabilities in making decisions about their own sexuality (Yool, Langdon, & Garner, 2003).

The wishes of family members, consent, and the legal system may become involved in the sexual lives of older adults with disabilities, particularly when those adults live in nursing homes. For example, Mr. Rayhon was recently arrested mere days after his wife's death on charges of sexually assaulting Mrs. Rayhon, not because she did not consent, but because Mrs. Rayhon's doctor and daughter decided she was unfit to consent to sexual activity due to dementia (Belluck, 2015). It was decided that Mrs. Rayhon's failing memory and disinhibition caused by dementia reduced her ability to make decisions and thus she was unable to legally consent. Although Mr. Rayhon was found innocent due to a conflicting account of what day the alleged sex occurred, such legal cases spell out the importance of analyzing the philosophy of capacity to consent. Arguments such as these, although worthy of generating concern, create an all-or-nothing cut off for consent based solely on ability rather than the wants, desires, context, and safety of the individuals. Furthermore, they suggest that family members and professionals hold a significant sway over the relationships people with disabilities under the guise of concern. Although studies have shown that even though older adults with dementia sometimes experience increased sexual expression and even sexual aggression, many retain their desire for healthy sexual expression, intimate touch, and companionship (Frankowski & Clark, 2009).

Due to the rapidly increasing population of people living with dementia (often caused by Alzheimer's disease) in nursing homes, and the legal balancing act required of nursing home staff, legal experts have weighed in on various controversial and difficult topics (Tenenbaum, 2009). Tenenbaum, for example, states that when a married partner is placed into a nursing home because of dementia, there is a strong chance that adultery will occur in the residence, leaving the staff and spouse to decide whether or not to intervene in the affair. Tenenbaum outlines the lengths that some nursing homes have gone to in order to present such sexual expression:

restraints, putting clothes on backwards, putting clients in zipperless jumpsuits, punishments and threats, restricted privacy and so on. Others suggest that nursing homes being predominantly run by religious organizations may use their own morality to enforce strict sexual guidelines on residents (White, 2010).

Some have suggested that although the law is not meeting the justice needs of women with mental disabilities, new laws and special provisions are not needed as a solution in order to protect women (Benedet & Grant, 2007). They suggest that, since it is already a crime to have sexual contact with a person without consent, special laws for people with disabilities (such as section 153.1 of the Canadian Criminal Code) offer nothing new to actually protect people with disabilities from sexual abuse. In the Canadian Code, sexual assault is deemed to have occurred when sexual contact is engaged in without consent, no consent is deemed to have been obtained if the person is incapable of giving consent, or if the accused is abusing a position of trust, power, or authority. Further, consent is not mere acquiescence to sexual activity, but requires a positive indication of a desire to participate. It is not adequate enough to suggest compliance is the same as consent, especially in the case of mental disability as someone with significant impairments may not know that what they want matters. Perhaps the greatest issue present in trials regarding the sexual assault of people with disabilities, is that intellectual disability is either ignored (and the person is assumed able to consent) or disability is used to infer consent (stereotyping the person with a disability as hypersexual or using sexual favours to fit in) (Benedet & Grant, 2007). Courts may be reluctant to invoke the language of incapacity to consent because judges may concern their decision with the autonomy of the person with a disability which inadvertently justifies the acquittal of the accused.

Sex Addiction as Disability

While the sexuality of some people with intellectual disabilities is sometimes perceived to be difficult to control (Gilmore & Chambers, 2010), there is a growing concern among researchers and the general population regarding the issue of sexual addiction: sexuality that is “out of control” (Bancroft & Vukadinovic, 2004). While not yet considered a disability or an official disorder in the DSM-V, sexual addiction is a much debated issue among sexologists and psychologists, as well as in pop culture and various media outlets. The issue of sex addiction presents the complexity of how one’s perspective on sexual behaviour influences ideas of impairment as well as the importance of behaviour in context (Coleman, 2003). For example it is typical for both adults and youths to have periods of intense and prolonged sexual interest such as with puberty or when in newly formed romantic partnerships, and it would be considerably harmful to identify typical and harmless states such as these as disabling rather than normal developmental phases. Furthermore, regarding addiction to internet pornography, it has been found that cultural factors such as religiosity and moral disapproval of pornography are strong predictors of perceived addiction, unrelated to the actual levels of use or time spent on the supposed addictive behaviour (Grubbs, Exline, Pargament, Hook, & Carlisle, 2015).

While sexual addiction has as no formal diagnosis, nor is there agreement between theorists and researchers as to the cause or underlying problem, typical notions include a variety of extraordinarily intense obsessions with sex and out of control compulsions towards sexual behaviours that result in real or perceived distress or harm (Coleman, 2003). Some have proposed that more than one mechanism has an influence on the symptoms of sexual addiction: a tendency to experience a large increase in sexual interest while experiencing anxiety or

depression, dissociative tendencies, and obsessive compulsive mechanisms (Bancroft & Vukadinovic, 2004). Davis (2012), a disability advocate, asks us to ponder a future where sexual addiction is codified as one such disorder: “What would it mean to understand sex addiction as disability?” (Davis, p. 313). Perhaps Davis’s most challenging notions revolve around how governments ought to insure sex addicts have an inclusive work place and the role of government in providing support: should sex addicts receive time off work to masturbate or have sex with a partner? Sex addiction recalls questions which have been asked regarding other disabilities: should they receive government funding to purchase the services of sex workers as is proposed for people with physical disabilities who cannot find partners? Is a person able to give consent where the disorder is believed to cause a person to become too consenting as is often cited when considering people with intellectual disabilities?

Conclusion

The ethical demands placed upon those who care for people with disabilities is extraordinarily high when it comes to sexuality. On the one hand there is the demand to meet the needs and rights of those with disabilities to fulfill sexual development and expression, while on the other hand there is a demand to protect people with disabilities from that sexual expression and from sexual abuse. Those that care for people with disabilities may be caught in a difficult bind, be familiar with only one side of the issue, or lack the training and resources to support sexual expression. Sex addiction presents an interesting metaphor for the issues of sex and disability where many of the myths and concerns about people with disabilities pool together, most commonly the notion of out-of-control sexuality and being too consenting. The discourse of ethics, sex, and disability seem to point to a shifting perspective where increasingly people may

be labelled as unable to consent due to a lack of ability and fears of danger. Furthermore that danger may not solely be the potential harm to the person with a disability, but the liability of the intuition where the person resides. The current system appears prone to abuse by personal and moral objectors (such as family members or staff) which can influence restrictions on the rights of those with disabilities.

CHAPTER V DISCUSSION

This thesis project examined and explored issues surrounding the accommodation of people with disabilities in society with regards to their sexual development and sexual expression, as well as the complicated array of barriers which may restrict them. This discussion reviews the results of that exploration and suggests recommendations for future investigation.

The results of this examination of the literature on sexuality and disability indicate both congruent and incongruent areas between research findings and the personal experiences of people with disabilities. This appears to be the result of a tendency to make broad-based assumptions about the sexuality and sexual lives of people with disabilities, rather than focusing on the rich diversity of individual experiences of people with disabilities. For example, it is commonly stated in the literature that people with disabilities are presumed by the wider society to be asexual (or, if they are seen as sexual, then it is presumed they are heterosexual, hypersexual, or otherwise sexually dysfunctional) (Noonan & Gomez, 2011; Milligan & Neufeldt, 2001). One proposed solution to this discrepancy is the production of positive media regarding disability and sexuality (Shuttleworth, Roberts, & Mona, 2002) which has been taken up by various advocates, researchers, and sexual health experts among others in order to inform both people with and without disabilities (see Burcaw, 2015; Guldin, 2000; Kaufman, Silverberg, & Odette, 2007; Morrison-Gurza, 2015).

Sexual development is largely expressed as both a biological and social process fraught with potential barriers for people with disabilities. This tapestry may include factors such as medical treatments (Greydanus & Omar, 2008), biological effects from disabilities (Sipski & Alexander, 1997), evolutionary mating preferences (Buss, 2003), physical limitations (Taleporos

& McCabe, 2001), childhood nurturance from caregivers (Haroian, 2000), intensive medical interventions and surveillance, parental expectations (Jordan-Young, 2012), media (Dune, 2012) and much more. The implication from this research is that people with disabilities, although more likely to be thought of as asexual or heterosexual, are probably more diverse as a population with regards to gender identity and sexual orientation.

Shakespeare & Watson (2002) suggest that advocacy for the sexual development of people with disabilities has focused on definitions, the philosophy of disability, and advancing rights through those definitions. Both the medical model and the social model of disability were found lacking. The medical model, which emphasizes medical interventions to create a normative life, lacks solutions where treatment is ineffective and devalues the variety within human experience (Shakespeare & Watson, 2002). While the social model focuses on shifting the source of the impairment outside of the body and into the way in which society has been constructed (Crow, 2007). However, not all impairments can be removed with changes and accommodations in the social environment (consider phenomenological, hence internal experiences, such as chronic pain). Furthermore, some changes to the social environment which improve access for one person may suddenly impair another (Shakespeare & Watson, 2002). The social model of disability also runs the risk of speaking for people with disabilities who do want to explore the many ways medical advancements can change the body in the same way that the medical model can be imposed on the lives of those with disabilities.

These factors all come to a point when looking at trans and intersex issues. Within the medical model, a person seeking sexual reassignment surgery must be declared satisfactorily disabled by the essential nature of their sex/gender mismatching their embodiment (Spade,

2003). However, a baby deemed intersex for having too small or different looking genitals may be recommended for ‘corrective surgery.’ Such a child may be reassigned from an ambiguous sex embodiment (gonadal/chromosomal) to female (e.g. removal of male or mixed gonads; creating a surgically constructed vulva and vagina), embracing a social constructivist approach to sex and gender while disabling the sexual organs in the process (Wilkerson, 2012). This instance represents an approach which seeks to normalize the sex/gender binary system, alternately employing opposing philosophies (essentialist and social constructivist) to satisfy the prevailing social norms.

Some have suggested the creation of a sexual culture for people with disabilities in order to liberate from oppressive norms (Siebers, 2012). Posing a difficult reality that many people with disabilities simply do not self-identify as disabled, and many wish to be normal, focusing on their culture, gender roles, or sexual orientation (Shakespeare & Watson, 2002). It would be just as much of an injustice to impose a “disabled” identity on someone whether it comes from a medical professional or an advocate. Sakellariou (2012) points out that the ways people with disabilities do produce a sexual identity have not been acknowledged or have otherwise been restrained by society, that “care practices have often been disempowering and controlling, constructing disabled people as objects of care and locating them in the place of a passive receiver and as a burden” (p. 191).

Foucault’s (1998) discursive concept of problematisation highlights the difficulty in solving problems related to sexuality and disability through regulations and political solutions. This thesis noted that the process of problematisation involves the creation of a discourse in a particular vocabulary and syntax which limits the available solutions to a similar discourse. This

thesis connected that notion to the political nature of sex research (see Bullough, 1994) and to the push for sexual surrogacy, which is fast becoming a key issue with regards to sexual access rights for people with disabilities (Liddiard, 2014). Advocates in favour of improving sexual access for people with disabilities through sexual surrogacy (see Limoncin, et al., 2014; Shapiro, 2002) appear to be operating within the problematized framework which ignores deeper complexities. That is to say that a simplistic resolution to the problem of access is to provide payment for that access for all people with disabilities; although that may be a desired option for some, not all will be satisfied (O'Brien, 1990).

Regulation and violation of sexual rights are serious issues facing many people with disabilities, especially concentrated in institutionalized settings. In the past, some have faced sterilization, initially based on the social-political eugenics movement, but largely used to control the behaviour of people with disabilities (van Heeswijk, 1994). Although now outlawed in many countries including Canada, some fear that sterilization practices may continue, hidden by parents and physicians (Hamilton, 2012). Also of concern are the methods by which those who care for people with disabilities attempt the control sexual expression, such as socially inappropriate masturbation which can cause negative public reactions and, in some instances, self-inflicted damage to the sexual organs (Griffiths & Lunsky, 2000). A number of cases have been deemed extreme enough to use drastic solutions, such as sterilization procedures (Carlson, Taylor, & Wilson, 2000), to curb both self-harm and public displays of sexual stimulation; although researchers suggest an evolution towards more human behavioural shaping (Tarnai, 2006).

A number of studies suggest that people with disabilities experience sexual abuse at much higher rates than the non-disabled (Alrisko-Schmidt, Armour, & Thibadeau, 2010; Sobsey & Doe, 1991; The Roeher Institute, 1995). Charges of sexual abuse are predicated on consent, therefore, capacity to provide consent must also be established (Benedet & Grant, 2007). Decisions regarding the capacity of disabled individuals to consent to sexual activity are increasingly being made through various forms of psychological testing. This testing aims to reduce the burdens placed upon institutions caring for those with intellectual disabilities by providing greater clarity on the capacity to make consent (Kennedy, 1999). Similar testing has been applied to those with schizophrenia and bipolar disorders, leading some to suggest that no matter the severity of the disorder, patients are at risk of being deemed unable to consent to sexual activity (Mandarelli, et al., 2012). Although some suggest the methodology of determining capacity to consent is improving due to expanding knowledge of brain function and the applicability of neuropsychological testing of executive functioning (Kennedy, 2000), the abuse of such systems may still be taking place. As some have found, family members may influence such procedures in order to prevent sexual or romantic partnerships they disapprove of, especially where nursing homes are involved (see Belluck, 2015; Frankowski & Clark, 2009; Tenenbaum, 2009; White, 2010). The rights of people with disabilities may be caught between the competing desires to protect vulnerable people and the promotion of their sexual autonomy (Benedet & Grant, 2007). Testing as a means to restrict a person from being able to consent to sexual activity seems to run counter to the stated goals and mandates to encourage sexual development, rather than provided the necessary support.

Implications for Therapists

Disability and sexuality research presents a host of concerns for therapists. First, therapists must be aware of their own biases regarding people with disabilities and sexuality: as noted above the tendency to make generalizations which do not fit for all individuals with a disability is high. Second, therapists ought to make an effort to explore sexuality with clients whom have disabilities. This is reported as a neglected area in the healthcare profession, one which is rated highly unsatisfactory by people with disabilities (Kedde, Van De Wiel, Schultz, Vanwesenbeeck, & Bender, 2012), and which, if handled poorly, may result in a lower quality of life for clients (O'Dea, Shuttleworth, & Wedgwood, 2012). Third, to appreciate the ways in which people with disabilities do explore sexuality rather than the ways they do not; too often people with disabilities are placed into a passive category and receiver of help rather than an active, autonomous agent (Sakellariou, 2012).

Future Directions

This thesis supports and echoes the call of Shuttleworth, Roberts, & Mona (2002) that more needs to be done to study the effects of new media explicitly designed to promote sexual identity and access for people with disabilities. Although people with disabilities have taken to producing a variety of works (literature, film, websites, etc) that demonstrate ways in which they overcome barriers and challenges in the sexual realm, few researchers have explored the usefulness or relevance of these personal achievements or the applicability of such individual efforts to effect positive change in others. Additionally, researchers may look to a variety of online sources and communities used by people with disabilities to discuss sexual topics personally important to them. For example, Kleinplatz's (2006) study on "extraordinary lovers" was used as an example in this thesis for researching useful themes and applied similarly to the

personal experiences of people with disabilities in the BDSM scene (see Rubel & Stassinopoulos, 2007). Some studies have suggested that some people who provide direct care for people with disabilities are willing to assist with sexual needs in a variety of capacities, yet many are at a loss with regards to practical ways of helping (Hamilton, 2009). It is prudent to explore both the successful ways these care givers are currently providing assistance and practical ways in which those potential resources may be mobilized further.

Limitations

Various limitations exist in this thesis. This study pulls from empirical research, surveys, news articles, expert opinions, and the personal experiences of people with disabilities. It therefore is open to including all the limitations contained in those studies, surveys, etc as any biases and errors in their results is carried forward into this thesis. Another potential weakness is that of comparing “apples to oranges” in that the cited studies contrast large statistical data with smaller qualitative studies and/or the personal reflections/opinions of people with disabilities. However, in order to broaden the scope of this thesis and explore the limitations of broad-based assumptions with regard to disability and sexuality, it was necessary to seek out alternative forms of evidence that may have been overlooked in reaching those assumptions.

Conclusion

The barriers to achieving full sexual agency for people with disabilities are considerable, and time will tell if new approaches to solving those issues will be helpful. Although people with disabilities have a right to their sexuality and sexual expression, society does not always accommodate them and sometimes actively undermines their personal agency (van Heeswijk,

1994). Although we may be tempted to lay all blame on normative ideals, essentialism, the legal system, eugenics, myths about asexuality and so on. We must also be mindful in our rush to provide solutions as “care practices have often been disempowering and controlling, constructing disabled people as objects of care and locating them in the place of a passive receiver and as a burden” (Sakellariou, 2012, p. 191). Sexuality has become a considerably important part of our civic identity, one in which our liberty and happiness are intertwined with our sexual rights (Weeks, 1998), yet remains a point of leverage and control in the lives of those deemed less able. When considering future courses of action it may do us well to appeal to our own self-interest and the reality that we all exist on a spectrum of disability, “No one’s body works perfectly, or consistently, or eternally.” (Shakespeare & Watson, 2002, p. 26).

This thesis examines the great cacophony of diversity hidden behind the assumptions of society and trends in research. Through many channels advocates and people with disabilities explore ways to express and develop their sexuality in a world that contains difficult barriers. Though we are obliged as a society to make accommodations for all of society’s members, as those sexual rights are guaranteed, we must be wary of the tendency to make sweeping assumptions and generalizations which do not apply to all individuals with disabilities. Results found both congruent and incongruent areas in the research and in the personal details of the lives of people with disabilities. Hopefully this thesis will encourage others to create deeper research into this population in order to better represent their individual needs and the accommodations most appropriate within society.

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