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Everyday Lived-Experiences and the Domain of the Sexual As Explored By Four Physically Disabled Women

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Everyday lived-Experiences and the Domain of the Sexual
As Explored By Four Physically Disabled Women

A Thesis

Submitted to the Graduate Faculty of the
University of New Orleans
in partial fulfillment of the
requirements for the degree of

Master of Arts
in
Sociology

by

Ashley Volion

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Abstract

This thesis is an exploratory study of the everyday lives of four women with various physical disabilities and how these women came to view themselves as sexual beings. Using an intersectional analysis and in-depth interviews, it examines these women's perceptions of expectations of normalcy in regard to life style, body image, and sexual practices, especially the expectations of their able-bodied family members and friends. It also explores how these disabled women deal with the stigmas they encounter in their everyday lives. Special attention is focused on how disabled people are often viewed as asexual or without sexual desires. By contrast, this thesis highlights the sexual agency of the disabled and includes policy implications that entail new ways of defining sexual practices, as well as the need for sex education for the disabled.

Keywords: disability, gender, sexuality, Intersectionality theory, Poststructuralism

Introduction

According to the U.S. Census, at the turn of the millennium there were more than 22 million females aged five or older with disabilities in the United States who were living in a non-institutionalized setting (U.S. Census, 2000). Being one of these women, I am passionately interested in their well-being. While the passage of the American with Disabilities Act in 1990 made important strides toward improving the life chances and opportunities of disabled people, there is still much that needs to be done. The 1990s marked another watershed in the history of disabled Americans when the new field of Disability Studies was created in 1993. While this field has increased our knowledge and understanding of the lives of disabled peoples, it is still in its infancy. This thesis is designed to contribute to this new frontier of disability studies and to tackle some issues that, to date, have received sparse attention particularly issues that relate to gender, disabilities, and sexual practices.

This study explores the life experiences of women with permanent and visible physical disabilities as well as how they construct themselves as sexual beings. Using qualitative interviews directed toward developing narratives, it also examines if more interaction with other disabled peoples affects whether, when and how disabled women come to construct themselves as sexual beings. As discussed at more length below, this study will broaden the notion of what is “sexual.” When I am writing about “sexual” beings, I am not speaking of “sexual” only in a relational sense. Rather, I will argue that a person can be a sexual being whether she is alone or with a partner. In turn, the notion of “sexual practices” will be broadened to

include not only genital sex, but also a range of erotic practices that result in bodily pleasure (Foucault, 1979).

To date, past research relevant to this study has explored how women with physical disabilities manage stigmas associated with having a physical disability, their perception of an ideal body, and how they manage having personal care limitations within different aspects of their lives (Asche and Fine, 1997; Bordo, 2003; Garland-Thomson 2004; Gerschick, 2000; Siebers, 2008; Taub. McLorg. & Fanflik, 2003; Welmer, 1996; Wendell, 1997). Although, these various studies have touched on important issues, these issues have not been linked together when speaking under the rubric of one's sexuality. One of the main tasks of this thesis is to coalesce this information in order to explore how women with physical disabilities construct themselves as sexual beings. My working definition of a sexual being is an individual who recognizes or identifies herself as a person who desires erotic bodily practices and who views herself as capable of being desired by others as a sexual person. Thus, this thesis focuses on the construction of sexuality from the point of view of the disabled person, although much of the literature to date addresses how disabled people are viewed by the able-bodied.

Indeed, much of the mainstream sociological literature focuses on various "abnormal social roles" and "stigmas" associated with having a physical disability from the vantage point of able-bodied people. For example, much of the research from a Structural Functionalist perspective suggests that women with physical disabilities are viewed as having lax gender construction, are asexual, are unable to reproduce quality offspring and perform domestic duties, and/or that they lack

social value and human status (Asche and Fine, 1997; Bordo, 2003; Garland-Thomson 2004; Gerschick, 2000; Siebers, 2008; Taub. McLorg. & Fanflik, 2003; Welmer, 1996; Wendell, 1997). Because stigma, according to Erving Goffman, is an “attribute that is discrediting” (Goffman, 1963: 3), these attributes are looked upon as negative. Yet, as contrasted with Structural Functionalism, Symbolic Interactionists, like Goffman, George Herbert Mead and Charles Horton Cooley focus their attention on the meanings associated with social interactions and better highlight how the notion of “disabilities” is socially constructed. They also focus more on the interactional process itself, and, hence, give more social agency to the “stigmatized” in constructing their own self concepts and identities.

While both of these mainstream sociological approaches emphasize how social roles and social role-taking impact the disabled, over time we shall see how the vantage point of scholarly studies shifts from a focus on the normative social structure and social role expectations to more conflict-oriented views of normative social structures as defined by dominant groups. Here the focus shifts to how the vantage point of dominant groups treat the disabled not only as different, but also as “lesser” through the process of “othering”.

In turn, the vantage point of scholarly studies begins to shift from the vantage point of the dominant, able-bodied groups to more emphasis on the vantage point of the disabled. As this shift in vantage point takes place, even more attention is given to disabled people as social actors and/or as performers of discursive normative scripts. Because these more recent approaches also are more critical, they highlight the ability of the disabled to redefine and possibly resist hegemonic depictions of

the disabled as both “abnormal” and as “lesser”. For example, the more recent analyses of disabilities by Intersectionality theorists, Standpoint theorists and Poststructuralists introduce new and more critical directions into the social analyses of disabilities. Below I will discuss each of these theoretical perspectives in turn and examine various research findings that have been used to buttress or to critique them. First, however, I will discuss the rise of the Disability Rights Movement and the creation of the new field of Disability Studies.

The Disability Rights Movement and the Creation of Disability Studies

As historically has been the case for other marginalized peoples, the Disability Rights Movement was inspired and received momentum from other social movements. In particular, the successes of the Civil Rights Movement, the Women’s Movement, and the Gay and Lesbian Movement in the 1960s and 1970s paved the way for disabled people to recognize how social movements could address discriminatory practices. Prior to the rise of the Disability Rights Movement, people with disabilities could be discriminated against on a daily basis without legal recourse to help them fight such indiscretions. One of the first major events to spark the Disability Rights Movement was the protest in 1988 by students who attended Gallaudet University, a liberal arts university for the deaf in Washington, DC. The students were protesting to ensure that a hearing-impaired person, rather than a person with full hearing abilities, was appointed as President of the university (Shapiro, 1994). It was also in 1988 that Lisa Carl, a 21 year-old with Cerebral Palsy, sued an Oregon theatre and won after being denied access (Shapiro, 1994). While these events triggered collective action by the disabled, it took another two

years to finally get the Americans with Disabilities Act (ADA) passed. On May 22, 1990, the Americans with Disabilities Act was passed by the U.S. House of Representatives by a recorded vote of 403-20 (Paraplegia News, 1990). Two months later, this Act was signed into law by President George H. Bush on July 26, 1990 and became effective on January 26, 1992. The ADA was landmark federal legislation designed to open up services and employment opportunities to the millions of Americans with disabilities (ADA Bathrooms, 2005). The ADA protected disabled individuals from discrimination in employment, public accommodations, transportation, government services, and telecommunications. In short, the ADA was a major accomplishment for Americans with disabilities. However, before the passage of the ADA, several important grassroots organizations had worked hard to contribute to these political successes.

Two major grassroots organizations had the strongest impact on creating the political climate necessary to get the ADA passed (Shapiro, 1994). In 1983 Americans Disabled for Accessible Public Transportation (ADAPT) was formed. This grassroots organization was devoted to nonviolent direct action as a means of getting people with disabilities the resources they needed in order to be productive members of their community (ADAPT, 2009). The National Rehabilitation Association (NRA) was formed even earlier in 1923 when a group of State Administrators of Vocational Rehabilitation agencies met during the National Society for Vocational Education conference. However, it was not until 1936 that the NRA began to make the needs of persons with disabilities its priority (NRA, 2009). The main objective of the NRA was to eradicate employment barriers and increase

employment rates for people with disabilities. They also served as advocates for the disabled and spread awareness about disabilities.

As with other social movements, it took mass activism to pass the ADA. In March of 1990, ADAPT members engaged in protests, sit-ins, and marches in Washington, D.C. in order to pressure the U.S. House of Representatives into passing the ADA. The President of ADAPT, Bob Kafka invited Randy Jennings and his organization- the Texas Branch of the NRA - to participate in the protests and in other civil disobedient acts that were going on in Washington (Shapiro, 1994). Kafka and Jennings learned that the larger the size of these protest rallies, the more likely that the ADA would be passed.

When the ADA was finally passed, people with disabilities realized that they had the power to make social change. However, they also realized that they needed a formal institutional structure for writing about, analyzing and publicizing their needs and wants. That is why in 1993 a new interdisciplinary field of study was created by the Society for Disability Studies - the field of Disability Studies. Disability studies is an interdisciplinary field which focuses on the contributions, experiences, history, and culture of people with disabilities (Society for Disability Studies, 2010). Although, disabilities were written about long before Disability Studies was created, it was the creation of this new field that gave people a legitimate, academic and institutionalized means to examine and analyze disability. It also helped to publicize the social and political concerns of the disabled to a broader audience.

I will now examine the different sociological approaches to disability studies that appeared both before and after the creation of this new field. Particular attention will be given to the ways these theorists address both gender and disabilities. As I noted earlier, we shall see over time how the foci of these studies shift in a number of different ways. In particular, they shift in a more critical fashion from studies that view the disabled as largely passive and without social agency to a view of the disabled as active, social subjects constructing and transforming the world in which they live. Not surprisingly, this shift in portrayals of social agency corresponds with a shift from a focus on the vantage point of the able-bodied, to a focus on the vantage point of the disabled.

Structural Functionalism

Lax Gender Construction & the Disabled as Unisex or Asexual :

From a Structural Functionalist theoretical perspective, because disabled individuals lack one of the primary characteristics of the ideal body - control of the body - the more severe an individual's disability, the fewer gender and sexual expectations he/she will have to uphold (Gerschick, 2000). The architect of Structural Functionalism in the United States, Talcott Parsons (1951), stated in his theory of the sick role that everyone who is deemed as sick by others has two rights and two obligations. Their first right is the right to be exempt from normal social roles. In this sense, the sick or those who are deemed sick are excused from normal roles and, thus, are viewed as abnormal. The second right is the sick person's right not to be responsible for his or her condition. This places the individual in the sick role as the absolute or pitiful victim. However, there are some normative

expectations; those in the sick role should try to get better and/or seek medical attention (Parsons, 1951). Thus, the “sick person’s ” major responsibilities are to seek help and to try to rehabilitate themselves (although this perspective does not give adequate attention to whether such medical or rehabilitative assistance is available to all who are “sick”). Since severely, disabled women lack degrees of bodily control, clearly they fall under this rubric of the sick role.

Moreover, a Structural Functional perspective not only addresses how the sick role operates on the micro-level, but also how it functions in a larger, macro-level, societal context. That is, because the lack of control the disabled body embodies reveals to able-bodied individuals just how vulnerable the body really is, this can be a frightening concept to come to terms with - both for the disabled and the able-bodied. Therefore, it is functional for a society to try and cover up disabled bodies or to pretend that they do not exist. Since disabilities are hidden, normative expectations for gender construction and sexuality from the point of view of the able-bodied are not required and “do not exist” for the disabled.

Together, the inability of the disabled body to conform to able-bodied norms, along with the lack of gender and sexual expectations, makes physically disabled individuals appear as both unisex (indistinguishable from other sex) and asexual (without interest in sex) as contrasted to their able-bodied counterparts (Siebers, 2008). These types of perceptions are often held by able-bodied people. In popular culture, such unisexed and asexual views are exemplified by Mattel’s famous Barbie doll collection. The doll Becky, who is Barbie’s physically disabled friend, is dressed in a black track suit and white tennis shoes; whereas, Barbie is always dressed in

high heels and a dress or outfit that shows off her sex appeal. Although it is somewhat ironic that the disable-bodied Becky is the doll in athletic clothes, her clothing and appearance present her to a wider audience as a figure who does not embody the same amount of sexuality as her able-bodied friend, Barbie (Garland-Thomson 2004). This example suggests how gendered disability is constructed in American society.

Indeed, gender is constructed in many ways within many different cultures and subcultures. For example, in the United States today, ideal femininity is seen as passive, nurturing, and emotional; while, ideal masculinity is seen as strong, capable, and rational (Bordo, 2003). These ideas were reflected in Parsons' Structural Functionalist perspective when he discussed how gender roles within the traditional (male breadwinner/female homemaker) nuclear family were both complementary and functional when men played "instrumental roles" and women played "expressive roles." According to Parsons, this was the most "functional family form" in modern industrial societies (Parsons, 1955). Although never voiced as such, these ideal depictions do not include disabled individuals, but rather refer to individuals who are able-bodied and healthy (Wendell, 1997). This is part of a larger tendency in social discourse - what one might refer to as able-bodied solipsism - which means that dominant discourses speak as if everyone is able-bodied and, thereby, silently excludes disabled people (Kessinger, 2008). This able-bodied solipsism is generally referred to in the literature as the "invisibility of disability" (Davis, 2004).

The invisibility of disability is even evident when disabled people are intentionally presented as sexual. For example, Ellen Stohl, a woman with paraplegia, was photographed in her *Playboy* [1987] pictorial in multiple ways; none of which were in her wheelchair. This *Playboy* pictorial was supposed to be an innovative, ground-breaking spread that celebrated disabled people's sexuality. However, by capturing Ellen in pictures that did not include her wheelchair the magazine spread separated her disability from her sexuality. In other words, it was okay to mention that Stohl was disabled as long as she could "pass" as able-bodied, and the public did not have to see that she was disabled.

Disabled Women as Unfit to Engage in Biological and Social Reproduction

Following further along the Structural Functionalist line of thinking, if disabled people are not expected to perform normative gender and sexual roles - but rather are viewed as asexual, then disabled women also are seen as unfit to reproduce, unable to be caretakers, and as lacking the ability to perform domestic duties (Asche and Fine, 1997). While never explicit, this assumption is held within a heteronormative society. This, of course, is a social construction not only of patriarchy, but also of heterosexual patriarchy. Heterosexism refers to viewing heterosexuality as the normal or default and any other form of sexuality as not normal or as "other". In this sense disabled, women are viewed as "other" and "lesser" on a variety of dimensions as unable to perform the tasks required of women either sexually or domestically.

Another stigma or assumption associated with physically disabled women is that they are childlike precisely because they are viewed as unable to take on adult

roles. In the case of disabled women, they are viewed as unable to produce quality offspring or care for others. Similarly, because the recognition by others of an individual's sexuality is part of the transition to adulthood (Earle, 1999; 312), this may explain why the disabled are viewed as asexual (Taub, McLorg. and Fanflik, 2003). In short, they are treated like children or dependents regardless of their ages. Beckett (2004) writes about how she and her girlfriend (who is a wheelchair user) were unable to get double beds in a handicapped accessible room. She was assumed to be her lover's caretaker, therefore, hugs, kisses, and other sexual touching were seen as caring instead of sexual (Beckett, 2004). In such ways, the disabled are always put in a position of having to "come out" in regard to their sexuality.

Also, as Begum points out, many physically disabled women complain that strides are made in rehabilitation programs to address concerns about male sexuality enabling disabled men to participate in societal norms of masculinity; however, concerns about female sexuality get forgotten (72; 1992). This implies that disabled women are not sexual; therefore, if disabled women are asexual they should not display themselves in a sexual manner. For instance, in the *Internationalist* (1993) an article was written about DeVonna, a paraplegic who dyed her pubic hair hot pink. When her doctor saw her pubic hair, he stated:

"I know it is very hard to accept that you have lost your sexuality but you don't need to draw attention to it this way (Finger, 1992)."

The doctor's statement implied that paraplegia robbed DeVonna of her sexuality and her right to sexual expression. For DeVonna's doctor and many others, physical disability is thought to affect much more than the physical aspects of the body.

Presumably, for women with physical disabilities who are viewed as asexual, the stigmas that they are viewed as unfit or unable to reproduce are not surprising.

In turn, sex and the ability to reproduce are both inextricably linked to human status (Sieber, 2008). O'Brien states that a doctor once told him and a group of people with paraplegia, "You may think you'll never have sex again, but remember...some people do become people again." (O'Brien and Kendall, 2003). As this statement infers one's ability to have sex, as well as to embody sexuality, is much more than just a physical act. This statement raises another important point—namely inadequate medical care in regard to sex and sexuality. Gynecologists are less likely to ask women with disabilities whether they are sexually active (Welner, 1996). Presumably, if these women are asked if they have sex, most often, it is under the assumption that they are heterosexual.

While Structural Functionalism focuses primarily on micro- and macro-level institutionalized and normative structures in terms of social roles, Symbolic Interactionism focuses on the meanings given to social actions and social roles. This interpretative approach to Sociology has contributed immensely to our understanding of the roles and identities of disabled peoples as we shall see below.

Symbolic Interactionism

My study will draw from Symbolic Interactionism and especially from the works of Herber Blumer, Charles Horton Cooley, George Herbert Mead, and Erving Goffman when looking at how disabled people's self concepts are formed, as well as their identities. Herbert Blumer (1969) was the theorist who coined the term "symbolic interactionism". According to Blumer, there are three principles to social

interactionism. First, humans act towards things according to the meanings that they ascribe to them (Blumer, 1969). Second, these meanings come from the social interaction that one has with others in society (Blumer, 1969). And lastly, these meanings are modified and interpreted based on one's encounters with others (Blumer, 1969). Both Charles Cooley and Herbert Mead use these three principles in their theories when describing how interaction affects the behavior of an individual.

Charles Cooley (1967) developed the concept of the "looking-glass self". According to Cooley, the "looking-glass self" is based on three assumptions. First, we imagine how we appear to others. Second, we imagine how others judge us. Then, we develop the self that we want to portray to others based on the judgment we imagine others to have of us (Cooley, 1998). According to Cooley's theory, we have multiple depictions of ourselves. Our audience determines how we will depict ourselves within certain groups of people. Therefore, we show different sides of ourselves according to the social situation that we are in. For physically disabled women, the process of the "looking glass self" affects how they act in different social situations, as well as whether or not they claim their disability or try to disguise their disability (Taub, McLorg, & Fanflik, 2003).

Symbolic interactionist Herbert Mead has a similar theory of social interaction. Mead's theory states that consciousness, the mind, and the self develop in the process of social interaction (Ritzer, 2004). According to Mead, the "self" is created through three stages of social interaction: the play stage, the game stage, and the generalized other stage (Ritzer, 2004). Throughout these stages, we learn to interact in society. The "play stage" is when a child takes on the role of a significant

other, such as their mother, father or teacher. The “game stage” occurs when the child matures and participates in group activities; it entails taking on multiple roles at the same time (Mead, 1913). The last in these three stages is taking the role of the “generalized other” stage. For Mead, the “play” and “game” stages enable a person to learn the social roles and the normative expectations associated with these roles in many and diverse social situations (Mead, 1913). It is through these stages that the self develops.

Moreover, for Mead the self is “reflexive” and has two phases the “I” and the “me” (Ritzer, 2004). The “I” is who we are as individual actors or subjects; while, the “me” is how we reflect back on ourselves as objects through our perceptions of how we are viewed by others (Mead, 1913). Hence, the self is not a passive entity but rather a “reflexive” one that filters and selects certain aspects of their world to internalize. In turn, the self is also a social actor who engages in what Goffman calls “impression management” in order to affect the way the self is presented to others in everyday life. In this way, Symbolic Interactionism gives more social agency to disabled people by discussing how their self-concepts are created through a process of social interaction in which they, like other social actors, are engaged. Through this engagement norms as well as stigmas are created.

Stigma and the Self

Erving Goffman takes the notions of Cooley’s and Mead’s socially constructed self and integrates them into his important work on stigma. Goffman discusses how individuals manage stigma in order to be viewed as normal (Goffman, 1963). Stigma is an “attribute that is discrediting” (Goffman, 1963: 3) and, therefore, these

attributes are looked upon as negative. These discrediting attributes that Goffman discusses range from physical deformities to blemishes on one's character (Goffman, 1963; 4). According to Goffman, all individuals have stigmas that they must manage on a daily basis. However, some individuals have more prominent and visible stigmas than others. Goffman would call physically disabled women the "discredited" or individuals who know they are stigmatized (Goffman, 1963; 4). The term "discredited" is usually used in regards to those who have a visible disability or abnormality. These stigmas are so ingrained into society that:

We use specific stigma terms such as cripple, bastard, and moron in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning (Goffman, 1963; 5).

Disabled individuals have to manage these everyday stigmas through the use of various methods. One of the ways that they try to combat the stigma associated with their disability is through the use of methods such as rehabilitation. Since disabled individuals fall under the "sick role" (Parsons, 1951), rehabilitation is used not only to ameliorate stigma, but also to make the disabled individual "well" or "normal" again. Rehabilitation can be in the form of physical therapy or other corrective treatments.

Other ways that people can combat the stigma associated with their disabilities include disguising the disability, thinking of their disability as a blessing, claiming a disability status, seeking sympathetic others, or isolating themselves from normals (Goffman, 1963). People with disabilities often disguise their disabilities by trying to make them less noticeable to others. For example, in a study

conducted by Taub, et al. (2003) on body image among physically disabled women, one respondent reported:

If I go to a party, I'll wear heels and stay off my feet all day long and walk in very slowly and wait til nobody's looking and lean on something or slowly sit down. Act like I don't have a problem, so that I can look good (Taub et al, 2003; 169).

Others who are unable to disguise their disability may claim their disability and use it to help others either in writing, activism, or some other form of outreach. An example of this could be found in the stories of writers such as Nancy Mairs (1999). Through her own personal memoirs she helps to inspire other disabled individuals who are looking for a voice. Disabled individuals also can seek sympathetic others that will help them cope through the rough moments associated with stigma. Finally, others may simply isolate themselves from normals all together. All of these stigma management techniques are used as defense mechanisms or as ways of dealing with the stigmas associated with their particular disability. While the notion of "stigma" gives a great deal of power to the normative structure and, thus, to dominant groups such as the able-bodied, Goffman is careful to highlight how the disabled act in various ways to deal with these stigmas. Thus, the disabled are not without agency in his theory even though his work does not have the critical edge of other theorists who highlight the notion of "othering" and the hidden hierarchies entailed in binary thought which I will now examine below.

Disabled People as "Other": The Work of Simone de Beauvoir

Feminist and existential theorist Simone de Beauvoir (1989) coined the term "women as other". Using this notion, she describes how there are always hidden

hierarchies in binary thought whereby the “other” is not only viewed as different, but also as lesser. Indeed, the “other” is often defined by what it lacks when compared to the dominant. If we look at various forms of binary or dualistic thinking that characterize much of Western thought women are viewed as lesser as compared with men; African Americans and other racial minorities are seen as lesser when compared with whites; and homosexuals are seen as lesser when compared with heterosexuals. For example, males are viewed as more rational than females, people of color are viewed as more animalistic or less civilized than whites, and heterosexuals are viewed as more “normal” than homosexuals. This dualistic thinking keeps “the other” degraded while the category that is seen as default holds the power.

Such binaries also operate for able-bodied and disable-bodied peoples. For example, a disabled individual under these binaries is often viewed as abnormal and less rational or childlike. I have noticed this in my own life experiences when, for instance, an able-bodied person has a question to ask me, he or she will ask the able-bodied person I am with instead of asking me directly. This is due to the perceptions that are embedded in this notion of “other”. Stocker states that, “We construct the other in order to form our own self identity” (2001:158). Also, when we group people together as “other,” we group them together as objects instead of identifying them as fellow subjects of experience that we might identify with” (Wendall, 1997: 116).

When we look at gender and disability together we see such binary thinking and hidden hierarchies at work. It is interesting, for example, that the majority of

disability literature is about women; fewer studies focus on men and the disabled body (Gerschick, 2000; Shuttleworth, 2004; Siebers, 2008). I would argue that this is related to normative views where women are seen as delicate, passive, and nurturing, while men are seen as strong, rational protectors. Thus, when individuals think about disability they automatically think about women because the strong, rational protector cannot be seen as flawed by disability. This analysis is suggested by Hanna and Rogosky's study (1987) where a class of undergraduates were given two pictures, one of a female and one of a male, and asked why they were in a wheelchair. A majority of the students attributed the woman's disability to an illness, while they attributed the man's disability to an injury. That is, some external powerful injury had to impact the strong, rational male to make him disabled, while women were assumed to come by their disabilities through more passive, internal means.

The coping mechanisms of the disabled also appear to be gendered. Studies, such as those by Taub, McLorg, and Fanflik (2004) and Shuttleworth (2004), suggest that disabled women are more likely to try to hide their disabilities than disabled men. Disabled men in Shuttleworth's (2004) study, for example, participated in risk-taking behavior, strived for occupational achievements, and controlled their own care. Although these men had struggles with masculinity, they did not try to hide their disabilities, but rather tried to overcompensate for them or make other attributes about themselves stand out over their disabilities (Shuttleworth, 2004).

Studies also have shown how the "otherness" of the disabled body pertains not only to the functioning or abilities of the body itself, but also to the ways in

which a disabled person is viewed as attractive or not. When we consider gender, we also know that there is a vast literature documenting how women are more likely to be judged by their physical attractiveness than men (Hanna and Rogosky, 1987; Asche and Fine, 1997; Taub et al, 2003). Today, in American society an emphasis is put on slenderness for women (Bordo, 2003), while for men an emphasis is put on a muscular or a V-shaped body (Drewnowski and Yee, 1987; Badmin, Furniam, and Sneade, 2002). Hanna and Rogosky's (1987) study documented how when students were asked what they associated with the words "disabled woman" they stated terms such as, "crippled, old, lonely, and ugly" (Hanna and Rogosky, 1987). Thus it is not surprising that in the majority of feminist anthologies, articles on disabilities most often will be found under sections on beauty and body image. However, no matter what the ideal "attractive" body may be in a given culture, achieving that ideal is all about controlling the body which can be rather difficult for physically disabled individuals.

It is for such reasons that disability theorists should follow the path of many feminists today who call for the demise of such dualistic thinking that divides social reality into binary categories, such as male/female, white/black, heterosexual/homosexual. These binary categories not only contain hidden hierarchies and inequalities, but also they limit the possibilities of being (Mack-Canty, 2005). Moreover, due to body image and other stigmas that affect women with disabilities, feminism is often seen as the perfect avenue in which to discuss and analyze issues faced by disabled women.

However, the articles written on disability in many feminist anthologies are few and far between. Moreover, when feminism and disability have been discussed, generally the writings highlight how disabled females experience a “double disadvantage” (Morris, 1993). This old “add and stir” version of discussing oppressions is inadequate precisely because different oppressions cannot be analytically separated out and then simply added together. Rather they are integrally interrelated and entail many other factors such as race, class, global/regional location and sexual orientation that affect women in a variety of ways. Take two physically disabled women, for example. One woman is a white, upper-middle class, heterosexual woman who lives in San Francisco; while the other woman is a Black, working-class, queer woman who lives in a rural area. Even though these two women are both physically disabled, they will not have the same life experiences due to these other factors. The feminist theoretical perspective that best tackles these complex issues is Intersectionality theory. Intersectionality theory has been used by various theorists to discuss women of color from the middle to late 1980s to the present (hooks, 1984; Crenshaw, 1989; Collins, 1990). However, it was not until the mid- to late 1990s that disabilities were put into such an intersectional, analytical context.

Intersectionality Theory and other Standpoint Theories on the Disabled

When dealing with disabilities, we have to take several factors into account. First, we must take the level of severity of one’s disability into account. While, two individuals may have the same type of disability, such as Cerebral Palsy, the severity of their disability may be different. For example, one individual with Cerebral Palsy

may not be capable of walking; while, another individual who has Cerebral Palsy may only have a limp. In her discussion of disabilities, Garland-Thomson also states, “disability signals that the body cannot be universalized. Shaped by history, defined by particularity, and at odds with its environment, disability confounds any notion of a generalizable, stable physical subject” (1997; 24). Disability fails to be generalizable because of physical or mental differences. However, it is also not generalizable due to each individual’s standpoint.

An individual’s standpoint refers to his or her social location in terms of social structural inequalities, such as gender, race, class, able-bodiedness, and sexual orientation. According to Standpoint theorists, because one’s vantage point or perspective on the world is intrinsically linked to their social location or standpoint, “the only way of knowing a socially constructed world is knowing it from within. We can never stand outside it” (Smith 1974; 28). Hence, the knowledge we acquire is never outside of our standpoint either. Harding states:

Knowledge is socially situated – knowledge is based on experience, and different situations result in different knowledges. But more than this is at stake. Oppressed groups “can learn to identify their distinctive opportunities to turn an oppressive feature of the group’s conditions into a source of critical insight about how the dominant society thinks and is structured. Thus, standpoint theories map how a social and political disadvantage can be turned into an epistemological, scientific, and political advantage.” (2004; 7-8).

Like many other marginalized groups, physically disabled women have a countless number of diverse voices. This is where intersectional analyses comes in. One of Intersectionality theory’s founding principles states that “intersection itself produces a particular experience of oppression- not merely the salience of any one variable, the working out of one vector” (Ritzer, 2004). In other words, all forms of

oppressions are simultaneous, interlocking and cannot be separated out. For instance, a Black, working-class, disabled lesbian is not oppressed just because of her disability. We also have to take into account her race, sexuality, class, and gender along with other factors that make her who she is. Intersectionality theorist Patricia Hill-Collins (1990) uses the term “matrix of domination” to suggest how every social location lies on a matrix of penalty and privilege, such that some groups - like Black males - can have privilege as males and still be oppressed as Blacks (1990; 234-235). Thus, it follows that disabled people are not all the same, but rather may have privilege on other dimensions of this matrix, such as class or gender privilege. In turn, their vantage points on social reality are affected by these different social locations. As such, Collins states that every individual has situated or partial knowledge and calls for polyvocality (many voices) and the retrieval of subjugated knowledges (knowledges of subordinate groups) in order to get a fuller understanding of the world around us (Collins, 1990).

Fellow Intersectionality theorist, bell hooks, in her book, *Feminist Theory: From Margin to Center* (1990), argues that marginalized or oppressed groups have more critical knowledge. Using the analogy of a railroad track that segregated African American residents from White residents in the town where hooks was raised, she argues that, because the African American residents had to go out into the White residents’ world to work each day, they were able to see the world as both an insider and an outsider on a daily basis. Similarly, it can be argued that disabled individuals are both insiders and outsiders on a daily basis as well. For example, because the world of everyday/everynight life in modern societies is constructed for

the able-bodied, everything from furniture to toilets are mass-produced and designed with the able-bodied and “average” person in mind. Indeed, the science of ergonomics is precisely the science of mass-producing objects for use by the average able-bodied person (Kessinger, 2008). Consequently, when an able-bodied person goes to an event, he or she does not have to put a lot of thought into it; whereas a disabled individual has to find out whether or not the event location has stairs and if the bathroom is big enough to maneuver in. While, the list of factors that need to be taken in account can be quite lengthy depending on the severity of the individual’s disability, the point is that the disabled are forced to navigate the world of the able-bodied in their everyday/everynight lives. Thus, hooks’ theory does not only apply to African-Americans, but also applies to all other marginalized or subordinated groups such as, disabled individuals, that are forced to live as an “outsider/within”. In contrast, dominant groups, such as the able-bodied rarely have to navigate the worlds of marginalized others. It is for this reason that hooks argues that marginalized groups have more critical insights - namely, the knowledge of two worlds and the inequalities they entail - unlike dominant groups. It is also for this reason that she calls for both the retrieval of subjugated knowledges as a critical act and for theory to move from the margins to the center.

Rosemarie Garland-Thompson (2002) draws on ideas of Intersectional analysis when she calls for an integration of disability studies and feminist theory. For Garland, like gender, “Disability...pervades all aspects of culture: in structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment” (531). Because of

the lens by which she looks at disability, disability pervades all aspects of one's being. Therefore, an intersectional disability studies not only would broaden the scope through which we view feminist theory, but also it would broaden the scope through which we see the world around us. Garland (2002) looks at four different themes when analyzing how disability can give a broader understanding to feminist theory- representation, the body, identity, and activism.

In her section on representation, she discusses how both females and the disabled (of both sexes) have historically been represented as "lesser" and as "other". She points to how females were looked upon by Aristotle as "mutated males", just as the term "monster" was used derogatorily to refer to someone with congenital disabilities (Garland- Thompson, 2002). Also, when analyzing the body, Garland discusses how females and the disabled (of both sexes) more frequently use cosmetic and reconstructive surgeries to attain normative ideals of beauty and appearance, just as both tend to hide these bodily manipulations so as to make themselves appear more "normal" or "natural"(Garland-Thompson, 2002). In short, both female bodies, as well as disabled bodies (of both sexes), are under normative social pressures to fix themselves. In turn, as Garland-Thompson points out, both women and the disabled (of both sexes) have developed various forms of activism (including collective activism) to combat these normative projections in recent decades. Such a comparison of the forms of resistance undertaken by women and the disabled (of both sexes) helps us to better see and to understand commonalities that could provide the basis for coalition work among these two marginalized and subjugated groups.

Poststructuralism on Sexual Practices and Disabilities

Michel Foucault's poststructuralist perspective (1978) on sex, sexuality and normality not only provides us with a different angle for viewing these topics, but also importantly discusses how the rise of notion of "normality" in regard to sex, sexuality and the body was ushered in by the new social scientific and medical sciences that arose in modernity (Foucault, 1978). It was the production of scientific "truths" about what was "normal" that gave particular discourses about sex, sexuality and disabilities such power in the modern world. Thus, for Foucault, knowledge and power are intrinsically intertwined. Moreover, power is not just found in hierarchical institutions or enforced from above by dominant groups, but "power is everywhere" because of the way discourses circulate and are internalized by people in everyday life (Foucault, 1979; 93).

To illustrate what he means here, consider how the following "expert" discourses define "sex" in contemporary American society. Some are exclusively heterosexual-oriented stating that sexual intercourse is a "sexual union between humans involving genital contact involving vaginal penetration by the penis" (Merriam-Webster Online 2009). Other sources try to be more inclusive of other sexual orientations by stating that sexual intercourse refers to "any physical contact between two individuals involving stimulation of the genital organs of at least one" (Dorland's Medical Dictionary for Healthcare Consumers 2009). Fifty years ago, such a definition would have been unheard of. Sexual intimacy, unlike sexual intercourse, is focused on the fluidity of sexual activity with one person with whom there is mutual emotional involvement (Brantley, Knox, Zusman 2001). According to these definitions, an individual who is

unable to receive sexual pleasure in the genital region is able to have sexual intimacy, but can never have sexual intercourse. However, if one takes Foucault's (1978) notion of "eroticism of the body" into account, sex can refer to a variety of erotic acts that can vary and differ from individual to individual while giving bodily pleasure. Therefore, by using his notion, sex can be seen as broad and fluid instead of narrow and restricted.

In turn, growing up, the majority of American children are taught that their genitalia are their erogenous zones and, thus, their primary sources of sexual pleasure (Siebers, 2008). Therefore, any sexual practices that fall outside of these traditional erogenous zones are not seen as normal sexual practices or as sexual practices at all. In high school sexual education classes, students are taught about safe, primarily heterosexual sex, practices, and about the human anatomy. However, they are not taught about other sexual practices and other methods used to engage in sexual activities. This excludes the sexual practices of many disabled individuals as well as the practices of people with diverse sexual orientations.

Erogenous zones, as learned from various disabled persons, reflect the more fluid notion of sexual practices Foucault was referring to with his notion of the "eroticism of the body" (Foucault, 1978). In fact, for many disabled people, sexual practices do not have to involve one's genitalia at all. Many people with physical disabilities reported heightened sensation in other parts of the body, such as the neck and earlobes (Siebers 2008, Wilkerson 2002). Therefore, by broadening the definition of sex, people who participate in diverse sexual practices, such as the disabled, can start to see themselves as being included as sexual beings.

In other words, because of the limitations that the disabled body can present, physically disabled individuals have to use alternative methods to engage in various intimate activities that often entail the decentering of sex from the genitalia. For example, in a study of forty-eight physically disabled men conducted by Shuttleworth, one of his respondents stated that he used his feet to give his girlfriend a backrub because both of his arms are amputated (Shuttleworth, 2004). In another instance, Siebers (2008) mentions two individuals, one woman with paralysis and one woman whose legs are amputated. Each of the women mention that, because of their respective disabilities, they are great—each in their own way— at giving their partners oral pleasure. One of the respondent’s girlfriends in Shuttleworth’s study stated that, “disabled men made much more sensitive lovers than nondisabled men” mainly because disabled men are forced to be more communicative due to the physical obstacles they have to overcome during intimate relations (Shuttleworth, 2004). In turn, even such factors as needing help with toileting can be an opportunity to engage in sexual activities according to disabled individuals. For instance, a physically disabled individual can go in the stall with his or her partner and engage in sexual activity (Kaufman, 1999 cited in Siebers, 2008). Thus, what are often perceived by able-bodied people as limitations of the disabled body can actually provide avenues for diverse and, sometimes, even more pleasurable forms of sexual experiences.

Through the use of Standpoint Theories, Intersectionality Theory, and Foucault’s “eroticism of the body,” notions of sex and sexuality can be broadened. By broadening these notions, physically disabled individuals can have a wider lens

through which to view themselves as sexual beings. In the next section, I will discuss the research methods employed in this study of how four women born with various, severe, physical disabilities dealt with their lives and themselves as sexual beings.

Methodology

Procedures

Three in-depth, semi-structured, interviews were conducted with each of my four respondents. The interviews were comprised of ten open-ended questions. From those open-ended questions, probing questions were then asked in order to get the respondents to think more deeply about the question at hand. Prior to each interview, each participant was given an informed consent form and asked to sign it. They also were given a copy for themselves. I explained that the study was completely voluntary and that they could opt out of any question or the entire study at any time. Before beginning each interview, participants were asked if they had any questions or concerns. Each interview lasted anywhere from thirty minutes to an hour and a half. Lastly, after each interview I wrote up field notes. These notes included comments on the tone of voice, mannerisms, and body language of the respondents.

The first interview was focused on childhood. Within the interview, the following were emphasized: social background (family, location and class of origin), definition of one's disability, in home responsibilities, memories, and goals and

dreams for the future.¹ For this interview, my questions did not explicitly ask about sex or sexuality. Rather, it was my goal to get a better understanding not only of the respondent's background, but also of their socialization process.

The second in the series of interviews focused on adolescence. In this interview, I asked questions about what my participants' experiences were like during this period in regard to issues like dating, peer interaction, obstacles faced, and their goals and dreams. By asking these questions, I was able to further understand the forces that played a role in how my four respondents constructed themselves as sexual beings. I wanted to see if the respondents faced any obstacles, and if so, how they combated these obstacles. In turn, I wanted to explore what, if any, affect these obstacles had on how my four respondents constructed themselves as sexual beings. The final interview focused on adulthood to the present. In this final interview, my questions focused on the themes of the previous two interviews as well as what particular issues and concerns respondents were passionate about and their social involvement. I also asked questions about if and when they came to view themselves as sexual beings and how they displayed themselves as sexual beings. I also received information on the construction of my respondents' selves in everyday life. Lastly, I asked if they had any questions or anything else they would like to share. From the information gathered by these three interviews, narratives of the lives of my respondents were developed.

¹ A list of all the interview questions used in each interview is attached in the appendix. There were also probing questions that were used which varied according to the respondent that are not included.

The narratives of the lives of my respondents that developed allowed my respondents to gain a more in-depth and deeper understanding of their lives. Skinner, et al (1999) stated that narratives allow respondents to recount their experiences as well as give them a means by which to create understanding about their lives. Also, the development of their narratives allowed me to understand the underpinnings of their lives as well. Through the development of these narratives, I was then able to situate their stories in a larger sociological context.

Research Population

My research is an exploratory research project that provides an indepth look into the lives of each of my four respondents. Due to the nature of my research and my small sample size, I make no attempt to generalize to the physically disabled population as a whole. Everyone has different experiences when it comes to disability. However, it is through each of their narratives that the reader will obtain a greater understanding of how these four women have constructed their lives and themselves as sexual beings.

The conditions of my study were as follows: all respondents had to be 18+ and women born biologically with a permanent and visible disability. It was my goal to interview a maximum of six people in order to explore how they constructed themselves as sexual beings as in-depth and as fully as possible. My final sample size of four respondents is detailed and sufficient due to my comprehensive and exploratory look into the lives of each of these four individuals.

Ethical Considerations

The first ethical issue in my study was ensuring the confidentiality of my participants. In order to ensure confidentiality, I asked each of my respondents to pick a pseudonym that could not be traced back to them. After each individual picked their pseudonym they were then referred to by their pseudonyms throughout the study (i.e. interviews and transcripts). Also, transcripts are kept in a locked filing cabinet in the Sociology Department at the University of New Orleans. The second ethical issue in my study was ensuring accuracy. Above all, I wanted to make sure that my study was written in a way that accurately represented the views of my respondents. In order to foster this, I allowed all four respondents to read my findings and analysis. In turn, I listened to each interview a minimum of three times so that I could find any inaccuracies as far as the content is concerned. I also personally transcribed every interview.

Lastly, I have to take into account my role as researcher. I am a 25-year-old white woman from a working class background who has Cerebral Palsy. I grew up in a small rural town in Southeast Louisiana along with a younger sister and a younger brother. Due to the small population of the community, I was the only person in town with a physical disability. Currently, I am a Sociology graduate student at the University of New Orleans. Because I am an “insider” in this study, I have taken the utmost care to ensure that my own biases and assumptions do not distort this study. For that reason, I began journaling. For instance, if something happened throughout the day concerning my disability, I wrote it down in my notebook. By engaging in the process of journaling, I was able to vent my own thoughts and feelings, while also separating these thoughts and feelings from my thesis work.

Limitations

There are several limitations to this research study. This study included a small, homogeneous group of four respondents. All of my respondents were white, middle-class, heterosexual women. I had intended on having both a class, as well as a racially diverse sample.²

All of my respondents have physical disabilities that were acquired from birth, and they all have some level of college education. Their educational levels range from pursuing an undergraduate degree to pursuing a Ph.D. Finally, their ages range from 25 years of age to 34 years of age.

Getting access to disabled individuals proved to be difficult. I recruited the help of local universities, as well as local disability organizations. However, the recruiting process was done primarily through e-mail. Ideally, I would have met with and built relationships with salient people in each university and organization. The fact that that New Orleans is a largely inaccessible city to the disabled and makes it difficult for people with physical disabilities to live here, also may have contributed to my low return rate.

When I originally started this project I naively thought that physically disabled women would be more than willing to talk to me because I am a physically disabled woman. I was under the impression that being interviewed by one's own or by someone from their own community would make my respondents feel more at

² The lack of racial and class diversity could be due to the fact that I started the recruitment process in the summer. Also, my recruitment e-mail and flyer was sent out by various local colleges in and surrounding New Orleans. Due to a lack of respondents, one of my respondents was referred to me by another respondent.

ease. For instance, researchers studying African-Americans often want Blacks to interview Blacks so that interviewees will feel more at ease (Royster, 2003). However, I was sadly mistaken about the advantages of “insider” interviewing. I only succeeded in recruiting four respondents. I also became aware that being an “insider” in my research could have its negative consequences as well. Isam (2000) wrote, “I would be the informant and translator, and therefore possibly the ambassador and traitor to the [my] community” (37). In other words, my research could be seen as having a positive impact for the disabled or it could be seen as having a “traitor status” to the disabled.

This research was not a simple process at all. I forgot to ask various questions that I thought of later on in the research process on multiple occasions. For this reason, I had to go back and ask my respondents more questions two and, in some cases, three times. If it was not for my small sample size, I would not have been able to do this. It must also be stated that due to medical reasons I was unable to contact one of the interviewees again to ask her follow-up questions.

Even with all these limitations, this exploratory look into the lives of each of these women enabled me to see patterns and commonalities, as well as the complexity of each one of their lives.

Data Analysis

Over the course of five months (June 2009- October 2009), twelve interviews were conducted and twelve transcriptions were composed. Each transcript ranged from 4 to 13 pages in length. Pseudonyms were employed to protect the confidentiality of each of my respondents. Respondents were asked to pick their

own pseudonym as well as the place and time of each interview. It was my goal to make them feel a part of the research process, relaxed, and comfortable in their interview settings.

Coding

In this study, I used inductive open coding to generate categories of information (Creswell, 2008). I coded each transcript by hand. I created a codebook comprised of every code and definition. Through inductive open coding the following codes were created: descriptions of disability, perceptions of norms, family, activities, limitations/obstacles, strategies and social interaction. However, these could change or expand. Descriptions of disability were coded for when participants self-define their disability. This code came from the use of this question: When you were growing up, how did you like people to refer to your disability? The next code, perceptions of norms, included things that were mentioned about societal norms (i.e. sex, dating, accessibility, and so on). Family was coded according to family composition, location of origin, and family values. Family composition included all of the individuals that were included in each respondent's household. Location of origin referred to where each respondent was born and raised, and family values included morals of right and wrong that were instilled by the family. Next, activities were coded according to the activities in which the individual is/was involved. The coding for limitations/obstacles referred to those limitations or obstacles presented by their disability. Strategies were coded according to those strategies employed by my respondents in order to combat the obstacles and limitations presented by their disabilities. I also developed a code for sexual practices as well as for dating. Sexual

practices were coded through their own definitions of sex or any mention of engaging in sex. Dating was coded for by any mention of going out on a date or having, (in the case of my heterosexual sample), a boyfriend. Lastly, in coding social interaction I only addressed respondents' mention of peer interaction.

Through these codes seven themes emerged: expectations, normalcy, social interaction, coping mechanisms, perceptions of society, dating, and sexual practices. The themes in my study were found by grouping the codes into categories. Once themes were developed, segments of each transcript were assigned to each theme. Lastly, when I engaged in the process of restorying, I took the codes and emergent themes and incorporated them into my analysis.

Reliability and Validity

In regard to reliability, I listened to each interview a minimum of three times while reading each transcript to ensure that the recorded interview and the transcript matched up and were accurate. Also, I read and reread my transcripts numerous times to check for content and typing errors. Further, in the coding process I double-checked my codes to ensure that I was consistent when it came to the definition of the codes developed (Creswell, 2008). These precautions helped to ensure the reliability of my research. I also spoke with two of my academic colleagues about my understanding and analysis in order to get feedback and to see if others would share my understanding.

As far as validity is concerned, as previously stated, I present the readers with my own biases and background information. In turn, participants were given a copy of my findings and analysis and asked to look over the accuracy of the content.

Creswell recommends this process stating that, by doing so, researchers are better able to ensure validity in the process of member checks (Creswell, 2008).

Summary

My study is an informative contribution to social science because it explores the everyday life experiences of women born with permanent and severe physical disabilities. It also is a pioneering work in the study of sexual identity construction by physically disabled women. Because I, the researcher, am physically disabled, I learned how important it was for other researchers to take into account the benefits and set backs of being an insider. I consider this to be a sound research project because I checked the accuracy of the content multiple times and had multiple conversations with my academic peers in order to see if others would share my understanding. I am also confident that if this study were repeated under the same conditions, it would produce the same results.

Data Collection

Participants

Denise (25 years old):

Denise is a white, middle-class, heterosexual woman who has Cerebral Palsy. Denise can walk, but her Cerebral Palsy affects her motor skills, causes her to be shakey, and stunted her physical development by about five years. She was born and raised in the suburbs of southeast Louisiana along with an older brother and her parents who are still married. From childhood to the present, her peer group primarily included her brother and his friends- none of which were disabled.

Presently, Denise is pursuing her Bachelors Degree and lives independently in an apartment.

Cindy (28 years old):

Cindy is a white, middle class, heterosexual woman who has Spina Bifida. Because of her Spina Bifida, Cindy has minimal use of her arms and legs and requires assistance on a daily basis with her personal care. She was born, raised, and resides with her parents in their home which is completely wheelchair accessible in Southeast Louisiana. Growing up she attended regular mainstream schools and had a large group of friends. As in Denise's situation, Cindy did not have any friends that were disabled. Cindy is currently involved in a local Spina Bifida organization. However, she does not attend events regularly due to health issues and school obligations.

Currently, she is pursuing her Masters in Social Work.

Leslie (32 years old):

Leslie is a white, middle class, heterosexual woman who has Muscular Dystrophy. Muscular Dystrophy is a degenerative disorder that affects the muscles. When she was a child, she could walk. However, due to the degenerative nature of her disability she became confined to a wheelchair permanently in her 20s. However, she does not require personal care assistance. She was the middle child of six. She has two sisters and three brothers. Her family is Catholic and her parents are still married. She was born and raised in Kansas, but now resides in California on her own where she is working as a teacher's assistant and pursuing a Ph.D. in Education. Growing up, she did not have any disabled friends at school. However, she went to a summer camp every year that gave her the chance to interact in a disabled

community. Leslie also was involved in a mentoring program for disabled high school and college students. She is currently in the process of developing a writing group for disabled women.

Kela (34 years old):

Kela is a white, middle-class, heterosexual woman from rural Kansas who has Muscular Atrophy. She also had a younger sister and brother that had Muscular Atrophy, as well. Besides going to MDA (Muscular Dystrophy Association) Camp, her siblings made up her disabled community. Muscular Atrophy is a degenerative disorder that causes her muscles to atrophy over time. As she ages, her limitations will increase. Her parents are still married and she resides in Southeast Louisiana where she is pursuing a Ph.D. in Biology. She has personal care attendants to help with her daily personal care needs. In New Orleans, her disabled community is very limited. However, she still keeps in contact with her friends from MD Camp as well as other friends she made over the years.

Description of Participants

Name	Age	Education Level	Type of Disability	Level of Mobility
Denise	25	Bachelors Degree	Cerebral Palsy	-Limited motor skills -Can walk -Lives independently
Cindy	28	Pursuing a Masters Degree in Social Work.	Spina Bifida	-Power wheelchair user -Limited use of arms and legs -Cannot walk -Needs a personal care attendant to complete daily tasks -Lives with parents
Leslie	32	Ph.D.	Muscular Dystrophy	-Uses a manual wheelchair -Her disability is degenerative -Cannot walk -Does not require a personal care attend -Lives independently
Kela	34	Pursuing a Ph.D.	Muscular Atrophy	-Uses a power wheelchair -Her disability is degenerative -Limited use of arms and legs -Cannot walk -Requires a personal care attendant -Lives independently

Findings and Analysis

Everyday Life Experiences

Through the narratives of my respondents, I found three major factors that affected the everyday life experiences of each respondent as well as how each of the respondents came to view themselves as sexual beings. These factors are family interactions, peer interactions, and perceptions of the able-bodied. In the following section, I will discuss the following: the expectations of the disabled as taught by their families of the disabled to ensure that the disabled could take care of themselves or be self-sufficient, notions of normalcy as defined by the family and social infrastructures, social interaction with other disabled peers, coping mechanisms, and perceptions of the disabled by the able-bodied and perceptions of the able-bodied by the disabled. Through the subsections mentioned above, one can see the affects that family interactions, peer interactions, and perceptions of the able-bodied had on the everyday life experiences of each respondent and how they constructed themselves as sexual beings.

Expectations of the Disabled

The family played a vital role when it came to teaching my respondents what was expected of them and what to expect of others. These expectations included: expectations of daily living, behavior in social situations and even expectations of how their bodies are suppose to function. Expectations of daily living included chores during childhood and adolescence, as well as ways to be self-reliant. However, in some cases, the family's expectations of daily living were rather lax.

Both Kela (34) and Leslie (32) spoke about these expectations in detail. For

instance, Kela stated:

We were expected to keep our rooms clean...there were times when I would help sweep the floor with the broom...mostly we had to keep our rooms clean and help fold clothes. We dusted where we could reach...helped to take care of the pets. You know that kind of thing.

Leslie also stated such expectations:

One of the first things she [her mother] gave me to do was helping fold laundry. She'd say, "You can help fold the wash cloths." And eventually as I got older I became responsible for doing the family's laundry during the summer. She'd also get me to do dusting. There were a lot of cleaning things to do. I learned how to do the dishes. When we were kids we had a chart saying whose turn it was to do the dishes or whose turn it was to do this or that. And I was always a part of that. I grew up on a farm too. So, there was a time when my responsibility was to take care of the chickens, and collect and wash the eggs.

While both Kela's and Leslie's families expected them to participate in daily chores, Denise's and Cindy's families had rather lax views when it came to chores and other physical expectations. When asked about chores or other responsibilities, both Denise and Cindy had similar answers. Denise recalled, speaking of herself as well as of her able-bodied sibling:

We kind of had chores, but we didn't do them. [laughs a little] We were bad kids. We worked in the yard every Sunday... They [her parents] weren't really strict. They never had to be. We never got into trouble. We were kind of friends with our parents., and everybody really got along. It was nice.

When posed the same question, Cindy stated:

I didn't really have any chores growing up because of my disability, but I did have to follow rules. I had to be respectful of my family and my friends and older people. And I just had to listen to whatever my parents told me, and just basically be a good person.

Both Denise and Cindy were not expected to engage in chores or in other physical responsibilities. Denise refers to this jokingly by calling herself and her brother "bad

kids”. However, Denise did learn the importance of being self-reliant. She lit up when speaking to me about going to dancing school, learning how to drive, and living on her own. She said that she wanted to learn how to do things independently in case anything happened to her parents so that she would not be a burden on her brother and his wife.

Cindy identifies her lack of chores and other household responsibilities with her disability, while Kela’s and Leslie’s families gave them chores and other responsibilities that they knew they were capable of performing. Cindy’s family did not. However, it must be noted that Cindy has the most severe physical limitations out of all of my four respondents. Cindy has limited movement of both her arms and legs and has trouble doing basic activities, such as feeding herself.

Notably, however, all of my respondents were taught the importance of having an education. Kela stated, “My parents pretty much wanted us to focus on studying and get good grades which was good because that helped us to get scholarships to pay for college.” For all of my respondents acquiring a good education promised self-reliance and financial stability. Kela went on to say that due to her academic achievements her parents do not have to worry about taking care of her financially. A good education can provide the disabled financial stability, personal independence, and in some cases the resources to pay for their own personal care. The family played a vital role when it came to expectations of the disabled. The parents of my respondents wanted their children to be self-sustainable despite their physical limitations. Therefore, all my respondents had certain expectations that their parents wanted them to follow whether it had to do with daily chores or

educational expectations. The expectations of the disabled went even further to include expectations of normalcy as well.

Normalcy

Institutional Notions of Normalcy (From the Vantage Point of the Able-Bodied)

Each of my respondents learned about normalcy or what is perceived as normal through their family or other institutional settings. Some of my respondents had to fight to even be seen within their respective institutional settings early on in life. For instance, Kela stated:

Instead of going to the close grade school three miles away, my siblings and I went to the school ten miles away. Our district had four grade schools, two of which were not accessible. The school ten miles away was the closest accessible school —(the other was maybe 14-15 miles away).

Leslie's grade school, on the other hand, wanted to have her bussed to a different district because the schools in her hometown were not equipped with ramps and elevators. Consider the dilemmas associated with schooling voiced by the following respondents:

Kela recalls:

The closest grade school to us...where we were living we couldn't go to that school because we couldn't get into the library at that time because it wasn't ramped. So, we went to a different school that was all on one level. So, we had to get bussed to get to that school, and then when I graduated from high school they had to build a ramp on to the stage. So, that I could go up and go on stage.

Leslie also recalls a similar situation, "When I went to high school, it was a two-story building, and it didn't have an elevator. There was a big discussion about if I should even go to that school, and the district's idea was to bus me somewhere else."

Kela was bussed to a school ten miles away from where she lived instead of the nearest school that was only three miles away. In Leslie's case, instead of the schools making the appropriate accommodations (i.e. ramps and elevators), the school district wanted to take the easy way out and get rid of their disabled students. Leslie was almost bussed to another district until her parents got the school district to move inaccessible classes or find another way that their daughter could attend the classes she needed to graduate. Similarly, due to Cindy's apparent disability, Cindy's mother had to fight for her to be placed in "mainstream" instead of "special ed" classes. These experiences sent the message to these three particular individuals that they were abnormal and that they should be able-bodied.

Messages that told these particular individuals that they are "abnormal" or seen as "other" were not only sent through school institutional infrastructures, but also through activities that were sanctioned by these institutions. Leslie mentioned that she thought, "Schools have activities that are geared towards nondisabled students, and I know that I was left out of a lot of activities." When Denise spoke of extracurricular activities, she mentioned, "I was doing a couple of high school plays. But everything else was sports. So, I really couldn't do that much." Inside of the school's infrastructure, these individuals were not seeing others like themselves, and they were not seeing any efforts being made for their inclusion. With the exception of Cindy, all three of my other respondents mentioned feelings of exclusion when it came to school. Kela also mentioned that she felt like an "outcast" because she did not fit into any "cliques". Moreover, she felt like she was an outcast not only in school, but also in the larger society.

Kela, Denise, and Leslie all experienced the “invisibility of disability” in their immediate and daily social surroundings. Due to the invisibility of disability, many examples of the lack of accommodations provided by able-bodied society can be found in the stories of my respondents. As noted above, schools did not provide extra-curricular activities for the disabled nor accessible buildings. Also, because a vast majority of things (i.e. furniture, utensils, building construction) were designed with the able-bodied person in mind, obstacles faced by the disabled were also largely invisible in these social settings.

Family Notions of Normalcy

Ideals of normalcy were taught and reiterated by the family members of my respondents. When it came to her body and her parents’ ideals of normalcy, Leslie said that her parents wished for her to be “healed” and to have the ability to walk one day. According to Leslie’s parents, Leslie was one of the “sick” and she would have a better life if only she were healed. While her parents’ wishes were most likely well intentioned, they shaped Leslie’s hopes and dreams as both a child and as an adolescent. Leslie believed that she would grow-up to be able-bodied.

I dreamed of myself as growing up to be nondisabled. And I think that was something that was encouraged by my parents. Um they were very involved in prayer groups, and you know talked a lot about praying for my healing, so, I think for part of my childhood I imagined that I would grow up and not be disabled. And I wanted to grow up and get married.

Leslie’s mother also told her in detail what to look for in a male companion as far as dating and even marriage was concerned. Leslie stated the following in discussing a conversation she and her mother had once had when she was a teenager, “She thought I would end up with someone. But that it would probably be

someone that was older than me. Someone who had been burned before and knew what was important.”

Whether done intentionally or not, this statement made Leslie think, “What the hell? Do you think I can’t attract someone my own age? Of my own peers?” While her mother felt that she would probably be with someone who was “older” or who had been “burned before,” Leslie felt that able-bodied society expected her to be with someone who was disabled. For example she stated, “People would be like, “Aww how cute a disabled couple!” and I kind of felt like it was something that people would expect, and I didn’t want to follow something that people would expect.” Now that she has gotten older and begun to feel comfortable in her own body, she has dated a few disabled guys. Instead of rebelling against what her mother and other able-bodied people expected, she tries to follow her own expectations.

While Leslie recalled this one specific conversation about a companion with her mother, my other three respondents did not mention a specific conversation about the type of companion they should look for. Rather, they recalled the absence of such conversations with their parents, as well as with their peers. They also mentioned that the guys they were interested in wanted to be “just friends”.

Social Interaction

“My favorite childhood memories were at camp”

All of my respondents lacked consistent social interaction with other physically disabled individuals in their hometowns and within the schools that they attended. However, Kela and Leslie attended MDA Camp each summer during childhood and

adolescence. MDA Camp allowed individuals age 7-21 with Muscular Dystrophy to participate in a weeklong, overnight summer camp. These individuals were provided with a personal care attendant so that their parents did not have to attend and they could achieve a certain level of independence. Being around other physically disabled individuals proved to be a great experience for both Kela and Leslie. Camp brought more acceptance and understanding of their disabilities to these two respondents.

Kela stated:

I was kind of different depending on where I was. If I was in school I tended to be kind of shy and kept to myself a lot. Umm if I was at camp or with my camp friends I was usually a lot more outgoing. And uh kind of crazy..a practical joker all that kinds of stuff. So it just kind of depended on what I considered to be my peers at camp I had a tendency to be more of who I am in private you know friendly and open when I was at camp more so than when I was at school when you know when you get into early teen years when the teens start forming little cliques, things like that. I didn't really fit into any clique. And so that's when I think I started keeping to myself. And I did that pretty much through middle school and high school.

Kela thought that she could be who she really was around other disabled individuals; whereas, around able-bodied individuals she felt like an outsider. She felt that people at camp understood her better than did her peers at school because they had a common bond when it came to disability.

Leslie also mentioned that MDA Camp was an important part of her life. She stated, "I think some of my favorite childhood memories are from camp... It felt like a place where it was okay to be disabled, and you weren't the only one that was disabled. And people just kind of accepted that about you without thinking it had to be changed." For Leslie, camp helped her develop relationships with other disabled individuals and brought her feelings of acceptance and normalcy.

In turn, at camp, there were dances and other activities for campers to engage in. While, Kela and Leslie did not mention flirting or dating while at camp, they did mention forging bonds which in some cases resulted in lifelong friends. Some of the events that forged bonds, included: water balloon fights, shaving cream fights, and raiding the boys' cabin.

Camp brought to these two respondents similar positive experiences. Through these experiences at camp, they felt that they were not the "other," but that they were finally part of the majority and they could wear their disability with pride. However, these positive experiences were not enough to combat the expectations and views of normalcy that were projected by the able-bodied when they returned to their hometowns.

Coping Mechanisms

In order to combat their feelings of inadequacy in able-bodied society, my respondents each engaged in various coping mechanisms. Their various coping mechanisms primarily included isolation and trying to comply with the norms of able-bodied society. Kela for instance mentioned, "I kept to myself most of the time...I wasn't hugely popular." Due to the fact that she considered herself a "loner," Kela would eat by herself at lunch. She states later that, "I'm comfortable being by myself. I don't have to eat lunch with someone. I'm totally comfortable sitting at a table eating lunch by myself." By stating this, Kela was able to cope with her feelings of inadequacy and shyness.

Denise did not have many friends at school other than her brother and his friends. In school she said, "Kids were horrible." Due to the cruelty she experienced

as a child, Denise isolated herself from the other students all the way through high school. She stated, “[if I could go back] I would be a little more open with people, and try to let stuff go. If I would have forgiven the people who harassed me as a child, I would have had a lot more friends.” However, she protected herself through isolation and putting up emotional barriers between herself and others. Denise mentioned that she had been called intimidating. She believes it has to do with the fact that, “I don’t take anybody’s shit.” By having this attitude, she has shown everyone that she is not someone that they can take advantage of or pity and that she can take care of herself.

Leslie engaged in another coping mechanism. Leslie tried to comply to able-bodied society’s standards. Leslie mentioned a constant need to “fit in”. She stated:

I always wore leg braces, and there were only certain shoes that you could wear with leg braces. And I remember that being a big issue for me because I felt like I had to wear ugly shoes. Now it doesn’t seem like a big deal, but when you’re a kid wanting to fit in-it is. I do think I paid a lot of attention on how I could fit in, and whether I did fit in or not. And looking back, I did fit in a lot.

Author and Disability Studies scholar, Jenny Morris (1989) tells a similar story, “I try hard to accept my body and improve on it but it’s a losing battle. I’m bombarded with pictures of beautiful bodies and I just cannot compete, so I try to hide my flaws” (1989; 61). In both cases, these women were surrounded by bodies that were not like their own. Therefore, they felt that their bodies were not only flawed but unacceptable. So, they both tried to get their bodies to conform to what they saw and perceived as normal. Not only did Leslie want her clothing to conform to able-bodied society, but also she distanced herself from any mention of her disability when around able-bodied individuals. For instance when doing writing

assignments for class she said, "I'd tell a story about a group of girls, but anything that had to do with disability I took out of the story." During childhood and adolescence, she also kept her disabled friends who she met at camp separated from her able-bodied friends from school because she did not think they would understand one another. For instance, she thought that her able-bodied friends would not understand the issues faced by her disabled friends. She also did not want to be known to her able-bodied friends as the "disabled girl". By separating her two groups of friends she thought she could "fit in" better in both worlds.

Perceptions

Perceptions of the Disabled by Able-Bodied People in Regard to Sex

My respondents mentioned perceptions of sex they had about able-bodied people, as well as perceptions that able-bodied people had about them. One of Kela's friends, for instance, stated that she had not thought of disabled people in a sexual way until she read one of Kela's stories. She said:

I never really thought about gimp sex, and originally if I would have thought about it I would have thought "eww, but now I think it's really hot!" She told me one time- she said, "I would have sex with your brother if I wasn't afraid I was going to break him because he's so tiny.

In response, Kela stated: "Well you guys could find a way if you really want to. There are ways."

For many able-bodied individuals who have not come into intimate contact with people who have physical disabilities this is presumably a common perception. Often, the only exposure that able-bodied have to people with disabilities are from the media. However, the media rarely depict disabled individuals in a sexual light.

Denise also mentioned that a friend of hers once stated that she intimidated him because she was not like the “typical” disabled person. Denise was offended by this comment because she perceived herself as a very independent person and did not see her independence as something to be intimidated by. She also did not appreciate the fact that her friend had these preconceived notions of disabled individuals as being dependent. Even though a physically disabled woman (or man, for that matter) may have some physical limitations, one must take their abilities into account as well.

Moreover, many people tend to make assumptions about physically disabled individuals’ limitations based solely on their outward appearance. Kela mentioned that a friend of hers stated, “I would have sex with your brother if I wasn’t afraid I was going to break him because he’s so tiny.” And I was like, “Well you guys could find a way if you really want to.” Each individual has a different standpoint, whether able-bodied or disabled, no two people are alike. Therefore, one cannot generalize or make assumptions about disabled people as a group. Such generalizations or assumptions can limit a person and be very detrimental not only to their emotional needs, but also in some cases to their physical needs as well. Therefore, able-bodied individuals need to ask questions in order to truly know the facts behind each situation. Nothing is impossible, “you...could find a way” to do almost anything.

Perceptions of Able-Bodied People by the Disabled

Uncomfortable to Accommodate

Through their family, social institutions, and society each of my respondents developed perceptions about able-bodied people. Some of the most common things

mentioned were, 1) that able-bodied individuals would get uncomfortable if they had to be accommodating to the disabled, 2) that able-bodied people did not see disabled people as sexual beings, and 3) the able-bodied would feel uncomfortable asking the disabled out on a date. Kela mentioned the first perception when she was asked why she does not attend many social events:

I know there are other things, but usually when people plan out places to go they forget to ask if it's handicapped accessible. And a lot of places in this city [New Orleans] are inaccessible. I don't want to get someone to drive me, and then get there just to find out the place is not handicapped accessible. Then everyone else gets uncomfortable because they didn't think about checking. And it's like, "Yeah, you should have checked but you didn't, and now we all feel uncomfortable because I can't get in." Now, I have to go back to my house, and I wasted this person's time that took the time out to come and get me. It just feels uncomfortable sometimes.

She felt that her inclusion would mean that others have to make sure that the particular location is equipped to her needs. She only mentioned how the able-bodied individuals would feel, putting their feelings above her own.

The Domain of the Sexual

“Am I a Sexual Being?”- They Don’t View Me Like That.

The second perception that was held by some of my respondents was that they presume able-bodied people do not view the disabled as sexual beings. In Kela’s second interview, when speaking about whether able-bodied individuals viewed her as a sexual being she said, “I don’t think a majority of society cares one way or another.” Having such a perception of society also affects how individuals think of themselves as well. For instance, Leslie did not pay attention to how she presented herself to potential significant others until, at the age of nineteen years old, someone asked her, “Why do you wear such baggy clothes? You have a great body. You should show it off.” She replied that she had not thought about her body like that before. It was not until after hearing this comment that she became conscious of how she dressed and began to view her body as something to be desired. Now, she makes a conscious effort to dress in clothes that make her feel good about her body. However, before that comment was made she had never viewed her body as sexually attractive. Therefore, she thought that others would not view her body in such a manner either. Due to this way of thinking she needed confirmation from others to reaffirm that she was attractive and a sexual being. Leslie also mentioned the following about her first kiss, “It was a real confidence booster. It’s one thing when your friends and family say that you’re attractive, but another when someone you’re attracted to says it and confirms it.”

This was another way in which Leslie received confirmation of her attractiveness because of her perception that able-bodied individuals did not view her as a sexual being.

Because Leslie doubted her attractiveness and sex appeal, she did not notice or became very distrustful when guys tried to flirt with her. In high school Leslie recalled:

I remember being at a high school dance, and there was a friend of mine there that I really liked. I was probably a sophomore. He came up to me and said, "I really want to dance." And I said, "My friend will dance with you." I realized later that, that was his way of asking me. But I took it as, "Oh I'm not going to be good at that. So, so-and-so will just dance with you." The perception I had that no one would be interested in me.

In college, on the other hand, she recalled an incident when a guy bought her a flower at the bar:

A guy walked up to me and handed me one of these flowers. One with a little light in it and he hands me that flower and walks away. And I thought, "Oh this guy is probably thinking oh let me buy her a flower it'll be the nice thing to do." And so, I was really kind of embarrassed by it. And I was like whatever. And I figured out how to turn the light off so people wouldn't see that I was sitting there holding this flower.

In both instances, Leslie did not think that the guys were "hitting on" her. However, for those who were, Leslie saw them as having two major motives.

I mean I think it's still hard for me not to be distrustful, and I still question what their motives are. I think it's because in the past there have been certain guys who will come and talk to me specifically because I'm disabled. And either it's because they were not able to meet somebody, and they think "Oh this will be easy" or she's going to really appreciate that I'm talking to her. Or there are some men that would like to be with someone that's disabled because they would feel more in control of the situation. And while I don't think that of everyone that hits on me, I am cautious. And I guess I have to rely on intuition to tell me which is which.

As noted earlier, when Kela was asked how others perceive her as a sexual being she stated, "I would probably say a majority of people don't think about it one way or the other." She stated that she did not feel very attractive at times. However, her friends felt differently. Kela's friends felt that she was sexually attractive as communicated by the following quote, "I've actually had a couple of friends who've said that if I weren't as they call me, "terminally" straight, they'd...they'd have me." She continued by stating, "Unless people tell me one way or another, I just assume they don't think about it one way or another."

When asked if she dresses in a way that displays herself as a sexual being, she stated that she does not because she does not feel comfortable in sexy clothes. For Kela, the most vital confirmation of her status as a sexual being came from evidence of others' attraction to her. Unlike Kela, Leslie, even with confirmation, did not feel like a sexual being until she felt comfortable in her own body. Because of societal expectations of normalcy to be able-bodied and the stigmas associated with disability, both Leslie and Kela began to look at themselves as asexual or as someone that would not be thought of in a sexual manner. However, both respondents slowly came to realize that they are sexual beings. Leslie also stated that as her sexual experiences increased, viewing herself as a sexual being became easier. But it must be noted that for all my respondents viewing themselves as sexual beings was a slow, difficult and ongoing struggle.

Fantasies- "Intimate and Realistic"

For my respondents, sexual fantasies were about intimacy rather than specific sexual acts. Leslie did not have a specific fantasy, but rather, fantasized about guys

being naked and close to her. For Leslie her fantasies involved intimate interactions rather than the specific act itself. She stated, "I was mainly concerned about closeness and being naked with them, ya know. [laughs] But as far as specifics or as far as what was going to happen or where we were going to be, I don't think that's been a big part of what I was thinking about."

When asked about her fantasies, Denise stated as well that she could not think of a specific fantasy, but she did say this about her fantasies, "It's just the same guy as my first kiss. Just doing basic stuff. Nothing odd."

All of my respondents stated that their disability is present in their fantasies.

Kela stated the following:

When I was younger, I always imagined myself as non-disabled. Later, my fantasies became mixed -- in some I was disabled, in others I was not. They're still a bit mixed, but now I'm disabled in them more often than not. I think the evolution of my fantasies reflects my ability to accept myself as a sexual being.

For Leslie, however, she stated that she saw herself as disabled in her fantasies because she did not want to fantasize about anything that could not realistically happen. For both of these women, they wanted what they imagined to match what they saw when they looked in the mirror. As Leslie stated, the fact that they saw themselves as disabled in their fantasies also symbolized self-acceptance of their disability.

Crushes

When Kela and Leslie were asked about their first crushes they both provided me with lively, uplifting accounts. Kela recalls her first crush who was also her first and only boyfriend in 4th Grade.

My first crush.... thats a good question. My first and only "boyfriend" was in the fourth grade. Umm he asked me out by dropping a present on my desk as he walked by and he was like "oops look what I did." And The next time he dropped a note that said "Will you be my girl friend? Yes/No/Maybe." But I guess yeah technically can he be my first crush?

Leslie's first crush occurred in the 7th Grade, she described her first crush as:

My first crush was in 6th or 7th grade, and he was a triplet. And we were friends. Not that we'd talk on the phone or anything, but at school we'd say hi to each other. Or if there was time we'd talk to each other. And I just thought he was great.

She went on to say that she liked him for a few years, but had never mentioned anything to him about it. However, she felt that her friends did not encourage her to tell him although they would have encouraged their able-bodied friends. Therefore, it made her think that she was perceived differently than able-bodied individuals or not seen as a sexual being. This reaffirmed her perception that able-bodied people do not see her as a sexual being.

Denise stated that her first boyfriend in high school was her first crush. She recalled going to the movies and out to dinner with him when they went out on dates. When asked to describe him in further detail, Denise stated simply that, "He was an interesting fellow." For all of my respondents, their first crushes were boys who were able-bodied.

Cindy was the only respondent that chose to opt out of the question stating that she could not think of her first crush. For Cindy, the most severely disabled respondent, this was a difficult question. When asked about her friends or other aspects of her social life she answered with ease. However, when questioned about crushes or dating, she found it more difficult to answer.

Dating

Out of my four respondents, Denise was the only one to report having dated in high school. Leslie, however, reported dating in college and dating presently from time to time. Kela reported having only been on one date that did not result in anything more than talking. Cindy, however, reported never dating or engaging in sexual contact of any kind. When asked if she had or does date Cindy stated:

Um not really. No I did not. It was because of my disability. Most guys were not interested in me because of my disability. I had guy friends, but they were just platonic.

Kela and Cindy echoed a similar reply that guys tended to only want a platonic relationship with them or they just wanted to be friends. As Kela stated, after a while “you start to give up”. For Kela, “you start to give up” not only on dating, but also it was a constant struggle to view herself as a sexual being.

Even though both Denise and Leslie have both reported dating, they still find the dating process difficult. Nevertheless, they both believed that the fact that they are disabled helped them to sort through the “bad” guys and get the really good ones. They also stated that because of their disability they think that they judge people based on what is on the inside, rather, than judging people solely by their outer appearance. Hence, they view their perceptions as less superficial than most able-bodied people.

Bell hooks would say that the disabled have a greater understanding of the world because the disabled are on the “margins”. People on the margins have to look at the world from the “inside out and from the outside in”. The reason why the disabled have such an understanding is because they have to negotiate both the disabled world and the world of the able-bodied. In many instances, the able-bodied

world fails to be accommodating or to take the disabled's needs into account. Therefore, it is up to the disabled to manage.

Sexual Practices

Because of the difficulty some respondents had with dating, sexual intercourse proved to be problematic. Sexual intercourse was not only problematic for them physically, but also there was a lack of knowledge given to them in terms of sex education and the ways in which one could engage in sexual activity. Three out of four respondents stated that their parents never talked to them about sex. However, parental views and expectations were learned through their stories about others such as, their views on waiting until marriage to have sex.

Leslie was the only respondent who had engaged in sexual intercourse. Both Denise and Cindy stated that they were waiting until they were married to have sex. Denise stated that she was waiting to have sexual intercourse until she is married because it was against her religion to do so before then. Cindy, on the other hand, was just waiting for the "right person".

However, even with all of the difficulty and uncertainty associated with sex and dating all my respondents agreed that all people deserve the right to independence and that we all are sexual beings. All of my respondents believed that people have to be creative and think outside of the box when it comes to sexual practices and having a disability. Kela stated: "All people deserve a right to independence, and a right to an orgasm."

Self-Reflections

Through the narratives of my four respondents I saw aspects of my own life reflected in their stories. For example, I was able to reflect on instances in my own life in which I had tried to conform to able-bodied society. I had bought into the stigmas surrounding my “disabled” body and tried hard to make my body fit into the expectations and ideals of normalcy that I had seen reflected around me by my family, friends, and institutional infrastructures. I grew up in a small town where I was the only person that was in a wheelchair. I was bussed to a school in a different school district because the school in my town was not equipped with elevators and other accommodations. However, the elementary school that I did attend was fairly diverse when it came to race and ability. I had a lot of friends there of both diverse races and bodily abilities, but I still separated myself from my disabled friends once I was home.

One of the first vivid memories I have concerning my disability was one of my dad’s co-worker’s walking up to me and stating, “Every night I pray that God will let you walk. I’m so sorry.” The first vivid memory I have of my mother in the context of my disability is her calling a psychic and asking her if I was ever going to walk and the psychic stating that, “Yes, she will walk.” My mother was so happy. From that point on I made it my goal to walk. After that I thought that when I reached the age of sixteen I would magically have the ability to walk. I had a lot of hope. I went to physical therapy twice a week for the first 20 years of my life. This caused me to miss a lot of school, but I did not care because my ultimate goal was to walk. However, I did strive for educational excellence because that was my only major avenue for satisfying my own need for perfection. If I could not control my body I

thought I could control my mind. So, that is exactly what I did. With my high hopes of walking, I did not want to be associated with anyone who was disabled except for in school. Not only did I not want to be associated with anyone who was disabled, but also I felt like I was not one of them. In short, I was not disabled and no one could tell me any differently.

As sixteen came and went, I began to resent my disability as my friends began to go out to shows, sleep at each other's houses, and participate in other activities that I could not be a part of due to a lack of appropriate accommodations. As a teenager, I attended middle and high school in my hometown with all able-bodied peers. From the age of twelve until a year ago I did not have any disabled friends or associates. Other than the places that I could not go, I thought I had a pretty "normal" adolescence. I would go to the movies, out to concerts or have my friends sleep over at my house on the weekends.

However, one of my biggest experiences as an adolescent occurred when I was around the age of 14 or 15 which is when all of my friends started dating. Up to the age of 14, I ignored the fact that I was disabled or tried to ignore the fact that I was disabled the best that I could. I remember the day when I came to the realization that others saw me as disabled. I was at a party with a friend when I was about 14, and someone walked up to me and stated, "You're so pretty. If only you weren't in a wheelchair." I did not know how to take this. I was highly offended. What does the fact that I'm in a wheelchair have to do with whether I'm viewed as pretty or not? Because of this trivial comment, I doubted that I would ever be seen as a sexual being. The more I began to doubt this, the more I began to resent my disability and

feel that I would always be alone. My resentment of my disability and the fact that I did not have anyone to talk to about these issues caused me a lot of loneliness and depression until a few years ago.

Coming to these realizations has taught me about the character of people around me. Like my respondents, I think that my disability has allowed me to gain greater insight into both worlds- the disabled and able-bodied world- much like bell hooks' (1984), notion from of "from margin to center". To have a relationship with a physically disabled individual requires some work on the part of the able-bodied person whether it be helping the disabled individual do something as simple as getting something off a shelf or helping the individual to the bathroom. When I was a teenager, I lost quite a few friends because they only wanted to be accommodating when it was convenient for them. However, along the way I gained some pretty amazing friends that I know are there for me.

Until starting this project, I did not recognize where these problems stemmed from nor did I have the tools to analyze them correctly. However, through this research process not only did I recognize these issues and where they came from, but also I began to recognize how people often treat me in diminutive ways. For instance, able-bodied people sometimes treat me as if I'm helpless, asexual, and childlike which all are associated with the stigmas of having a physical disability that I encountered reading the disability literature (Asche and Fine, 1997; Garland-Thomson 2004; Siebers, 2008). For instance, I have been at parties wearing the same thing as an able-bodied woman. The comment that I receive most often is, "You're so cute."; while the next person will be told that she is "hot." I have noticed

in the last few months that when this happens my voice gets a little softer and I make myself a little smaller- like a child.

I also noticed that able-bodied people sometimes talk to others instead of talking directly to me. People tend to link my inability to walk to my mental capability. Yes, sometimes people that use wheelchairs are mentally incapable. However, people need to ask before assuming that this is the case. I rarely noticed when people did this before studying disability in such an analytical way unless it was done in a blatantly obvious way. Sometimes I still do not recognize when this happens. I also have noticed that I do not speak up in a lot of situations and I sometimes look to others to speak up for me. This was by far the biggest epiphany I had throughout this process. I am sometimes angry with how able-bodied people interact with me. But more importantly I had to realize how I react to the way able-bodied people interact with me and how I am complicit in these interactions. Able-bodied people will jump to do things for me that I can do for myself. For instance, I was punching holes in some papers and this person that I did not even know took them out of my hand and continued to punch holes in my papers. I do not mind help. Sometimes, I need help. For instance, if you're in front of me please hold the door. My point is not for able-bodied people to stop helping disabled people. My point is that able-bodied people should ask first if we need assistance. When I first started to realize all of these things, I was angry (and still am sometimes) primarily at myself for being so oblivious to all of these issues. However, I do realize that these are all issues that cannot be eradicated in a day, but that I must unpack all them. Just as writers such as Peggy McIntosh (1988) unpack

the privilege of whiteness, I need to unpack the privilege of able-bodiedness so that I can begin to combat and transform the discourses of disability.

I did not come to resent my disability out of the blue, but I was taught to resent it by an able-bodied society that told me that I took on the “sick role” (Parsons, 1951) and that I need to get “better” in order to conform to an able-bodied society. Because the disabled are expected to conform to an able-bodied society, sex and the ways in which a disabled person could engage in sex was never introduced to me. Due to this lack of knowledge, I realized at the age of 25 that I do not know how to use my own body. I learned that I resented (and to a certain extent still resent it every now and then) because I do not know how it functions. It was not until recently that I learned how to do something as simple as unbuttoning a pair of pants or holding myself up with the use of a bar. If I did not know how to complete simple tasks, one can only imagine the extent of what I knew about myself sexually. I can use only vague terms for most sexual positions, because I do not have words for them. I need to find out what my body can do. I do not know how to maneuver my body. I want to find different ways to compensate for my body’s physical and sexual limitations. However, this will also involve trial and error. This is a really hard thing for me to admit not only to others, but ultimately to myself. The fact that I do not know how my body works has caused various issues in my life. I had periods in my life and still to this day battle issues of feeling comfortable in my own body. Therefore, I kept myself in a box. You cannot go up to a person and say “I don’t know anything about my body. Can you tell me how it functions?” However, I realized that in sex education there was not a section on how the disabled body works and the

only sex talk that I received was from my grandmother who said, “If you have sex, you’ll get pregnant if you’re not careful.” However, no one ever explained the mechanics of it all. When I talk about not knowing how my body functions, I speak not only of knowing how it functions in a sexual manner, but also how it functions in a general manner.

Coming to terms with the issues surrounding my disability is an ongoing everyday battle. But it was through the research process and the narratives and experiences of my respondents that I began to reflect on the issues that were previously mentioned. By acknowledging these issues, I can begin to empower myself as well as others. I will be able to call people out on the things that they do that I see as problematic and I can begin to make them aware and educate them. I also will begin to see the various ways that I perpetuate the stigmas and negative associations of disability, in turn, educating myself in the process.

I now can say I own my disability and am grateful for the ways in which it has shaped my life both academically and personally. I have learned that more often than not one will see the negative aspects of their disability before they come to see the positive. All of my respondents, myself included, have dealt with the negative affects of having a disability before they were able to be comfortable with themselves and have pride in their disability. My disability has shaped my area of focus as far as academics are concerned. In my personal life, however, it is my disability that gives me strength and compassion. I will forever be grateful for having the opportunity to engage in such a wonderful area of research with such generous and open respondents. They have taught me a lot in the process and I hope

I have taught them something as well. Even if this thesis only reaches one person like me and puts them on the path to realizing the capabilities, not just the disabilities of their existence, then that would bring me satisfaction.

Before writing this section, I questioned whether I should add my own reflections on this thesis or not. It was one thing to be an “insider,” but I did not think as a researcher that it was my right to discuss how my research affected me— even though it did affect me in many ways. However, every researcher engages in some form of reflection or reflexivity throughout the research process. Reflexivity refers to “the ways in which the products of research are affected by the personnel and process of doing research” (Davies, 2008). Reflexivity also allows one to acknowledge that in social research one cannot be completely objective (Holliday, 2007). To be completely honest, I was scared of facing the issues and emotions that I would have to face when writing these reflections down on paper. However, through the interview process my respondents were asked to reflect on their lives, therefore, making themselves vulnerable. Through writing these reflections, I too, have made myself vulnerable. As Behar (2008) stated, “When you write vulnerably, others respond vulnerably.” Thus, the very recognition of reflexivity in research can be enriching to the research process.

Discussion

This thesis is divided into two sections: everyday life experiences and the domain of the sexual. First, one has to understand the factors that affect a person’s everyday life before one can understand how this affects one’s construction of themselves as sexual beings. Both Denise and Cindy did not have any disabled

friends. However, Kela and Leslie had a group of disabled friends that they had met at Muscular Dystrophy camp. While Kela and Leslie kept contact with these disabled friends, their group of disabled friends did not live in the same town nor did they attend the same schools. Hence, both Kela and Leslie were the only physically disabled individuals in the towns in which they grew up. This meant that both women were forced to assimilate into an able-bodied world on a daily basis. Because of their limited contact and social interaction with other physically disabled individual and because of their perceptions of the expectations and ideals of an able-bodied society, Kela and Leslie had and continue to have problems viewing themselves as sexual beings.

Kela and Leslie have degenerative disabilities; while, both Denise and Cindy's disabilities are not degenerative. There were no explicit differences in expectations, notions of normalcy, coping mechanisms, or perceptions of themselves and others associated with whether their disability was degenerative or not. However, when it came to the severity of one's disability there were differences. In this study, I found that higher levels of independence corresponded with an increased chance of dating or engaging in sexual activities. For instance, both Denise and Leslie had gone on dates with guys, but both Kela and Cindy had not. Both Denise and Leslie are fairly independent. They both live on their own and do not require assistance with completing everyday tasks. Both Kela and Cindy have very limited use of their limbs and need the help of a personal care attendant to perform everyday tasks. While Kela lives independently, she has personal care attendants scheduled to come out at specific times throughout the day and night to help her complete various tasks.

For all of my respondents, fantasies were more about intimacy than an actual sexual act. However, my respondents have not experienced enough sexual practices to answer the question of whether or not looking at sexual practices as fluid acts would affect how they constructed themselves as sexual beings. Going back to Foucault's (1979) theory of the "eroticism of the body," sex can refer to a variety of erotic acts that give bodily pleasure and these acts can vary and differ from individual to individual. For disabled individuals, and for these four women in particular, viewing sexual practices as fluid can help an individual to feel more like a sexual being. By viewing sexual practices in a more fluid manner, the notion of what is normal would also be broadened. By broadening what is normal, individuals with disabilities would begin to view their bodies more positively.

For all of these women, there were similarities but also differences in each of their experiences. While I set out to explore how these women constructed themselves as sexual beings (and I did get some insightful information), I received more in-depth information on their perceptions of normalcy and how they formulated and dealt with these perceptions.

In order to help disabled individuals feel more like sexual beings, there needs to be a more open discussion when it comes to disability and sex. Not only does this topic need to be discussed, but there needs to be more educational as well as other ways for disabled people to learn about the mechanics of their own bodies. Because of a lack of access to such resources, presumably some disabled individuals are unsure of how to even go about engaging in various sexual activities. By bringing disability and sex out of the shadows and providing education as well as new ways

of looking at sex, the stigmas associated with this topic can begin to be ameliorated. Most importantly, it would help disabled individuals to see themselves sexually in a positive and new light.

Suggestions for Future Research

After completing this thesis, I had the following questions: Would the narratives look the same if my sample was more diverse by factors such as, gender, location, class, race, and sexual orientation? Would the implementation of sexual education and sex-positive programs help to counteract negative stigmas put forth by society?

By taking such factors as gender, race, class, and sexual orientation into account researchers will be able to see how these factors interact with and affect the socialization process of the disabled. While, there have been some intersectional approaches to disability (Schriempf, 2001; Garland-Thompson, 2004), to date there are too few studies that take this approach and even fewer that discuss disabilities and sexuality. By having a broader understanding of these intersections, researchers could have a fuller understanding of sexuality in regards to the disabled.

As Foucault so aptly highlighted, knowledge is power. So, would more knowledge about the disabled body counteract negative stigmas put forth by society or give the disabled more sexual options? To research this question, one could conduct an experiment in which there are two groups- one group that received no sexual education and one group that attended sexual education and sex positive programs. During this experiment, the researcher could study the affects of sexual education and sex positive programs on the participants. Information concerning the disabled

body needs to be integrated into sexual education programs. By integrating this information into sexual education classes, the disabled would have the opportunity to learn about their own bodies, while, giving the able-bodied an opportunity to learn about the disabled body as well. Therefore, individuals would begin to understand how the disabled body operates, ameliorating false assumptions of the unknown. Also parents of children with disabilities should be taught about disabilities and sexual practices. By knowing more about the mechanics of the disabled body, parents would be more open when it comes to sexual practices and their disabled children.

Along with sexual education, there needs to be policy set in place in the United States to allow disabled individuals to obtain the help that they may need to engage in sexual intercourse or other forms of sexual expression, such as masturbation. For example, personal care attendants should be trained to help individuals with disabilities engage in various forms of sexual expression. Therefore, giving disabled individuals more options in which to engage in sexual practices. Besides sexuality and sexual practices, more studies should be done in deconstructing what is “normal”. Using a poststructuralist perspective, a mixed methods vignette study could be devised to see how Americans react to certain body types, and whether participants view these body types (able-bodied and disabled) as normal or abnormal. Then interviews could be conducted to inquire about how participants constructed their notions of normalcy. By engaging in such a research project, one could delve further into what makes a body normal or abnormal. Such a research project would access the fluidity in regards to physical ability. According to

Foucault's (1978) notion of normalcy in regards to sex, sexual practices are fluid. However, can normalcy in regards to physical ability be seen as fluid as well? As far as more general research on the disabled is concerned, I suggest that researchers embarking on similar research projects not use e-mail for recruiting purposes, but gain contacts and respondents through in-person meetings, organizations, and networking. I also suggest that researchers that engage in such areas of research not be afraid of asking the specific and sometimes difficult questions surrounding sexual practices and other related activities. The respondents know the nature of the study of research. So, the worst that could happen is that the respondents opt out of the question or questions asked.

In conclusion, as a physically disabled woman, this thesis has helped me to come to terms with how my family, social infrastructures, and able-bodied society's norms and expectations surrounding the body shaped my everyday lived-experiences as well as how I constructed myself as a sexual being. This thesis also has given me a way to analyze the stigmas associated with having a disability and has shown me ways in which I have internalized these stigmas in my actions as well as in my thinking. Such research is important for any disabled researcher because it not only allows one to have an in-depth look into the lives of the disabled, but also it allows for self-actualization and self-reflection. Due to this thesis, I was able to gain the ability to reclaim my own strength. Most importantly I gained pride in my disability.

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Appendix A: Informed Consent Form

Dear Participant:

I am a graduate student working under the direction of Dr. Susan Mann in the Department of Sociology at the University of New Orleans. I am conducting a research study that explores how physically disabled women perceive themselves as sexual beings through their own life histories.

I am requesting your participation, which will involve a series of three interviews that will last approximately one-hour over the period of three months. All interviews will be put on an audiotape and listened to by the co-investigator for transcription purposes. After the interview is transcribed and the study's findings are written, participants will be given a copy of the research findings. You must be 18 years of age or older to participate in this study. Your participation in this study is voluntary, and you will not be paid for your participation. I understand that the research subject matter is of a sensitive nature. If at any time you feel uncomfortable or experience feelings of emotional distress by a posed question, feel free to opt out of the question(s). If you choose not to answer a question(s) or to withdraw from the study at any time, there will be no consequences. The results of the research study may be published, but your name will not be used. It is my goal to publish a study in which you, the participant, will be proud to have participated.

The possible benefit of your participation is that others will find knowledge and strength from your story. Additionally, through your participation in this study you can possibly gain new insight about yourself as well. If you have any questions concerning the research study, please call Dr. Susan Mann at (504) 280-6601 or Ashley Volion at 504-259-2176.

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, please contact Dr. Ann O'Hanlon at the University of New Orleans (504) 280-3990.

Sincerely,

Susan Mann and Ashley Volion

By signing below you are giving consent to participate in the above study. You understand the procedures, benefits, and risks associated with this study, and you understand that participation is voluntary.

Signature

Printed Name

Date

Appendix B: Interview Questions

I. Childhood (Birth- 12 years-old)

1. Can you tell me about your childhood?
 - a. When were you born?
 - b. Where?
 - c. Siblings?
 - d. Parents?
2. Can you describe the area you grew up in?
3. Did you have any rules you had to follow growing up? Chores?
4. Can you tell me about your disability?
5. When you were growing up, how did you like people to refer to your disability?
6. Did your disability present any obstacles for you growing up?
7. Can you describe the schools you attended?
 - a. Friendships? With other disabled individuals?
 - b. Extra curricula activities? With other disabled individuals?
8. What was your most vivid childhood memory?
9. What dreams and goals did you have as a child?
10. If you could say anything to your childhood self, what would that be?

II. Adolescence (13 years-old- 20 years-old)

1. Describe yourself as a teenager?
2. What was your favorite activity to engage in?
3. What would you be doing on the weekends?
4. Who was your first crush?
 - a. Do you remember how old you were?
 - b. Describe your crush?
5. Did you date during high school/college?
6. Did your disability create any obstacles when it came to dating?
7. Who were your role models?
8. What did you want to do after high school?
9. What did you learn about yourself during this time period?
10. If you could say anything to your teenage self what would that be?

III. Adulthood-Present (21 years-old- present)

1. What are some things you are passionate about? Why?
2. What do you think has stayed the same about you throughout your life?
3. What do you think has changed about you?
4. Who are your role models?
5. Are you involved in any activities/organizations?
 - a. Has this involvement affected your life in any way?
6. As far as your personal life is concerned, in what ways do you display yourself as a sexual being?
7. Within the previous interviews I have asked about the obstacles that your disability has presented in your life, as an adult have these

obstacles had or do they still have any effects on you as a sexual being? Or on other aspects of your life?

8. Do you feel differently about yourself sexually now from how you felt when you were younger? How?

9. Can you tell me about the strengths or positive side to having a disability?

10. If there was anything you could tell people about having a physical disability, what would that be? What would you say in relation to sex and sexuality?

**University Committee for the Protection
of Human Subjects in Research**

University of New Orleans

Campus Correspondence

Principal Investigator: Susan Mann

Co-Investigator: Ashley Volion

Date: June 5, 2009

Protocol Title:“(De)Centering Sexuality: Narratives of
the Physically Disabled Woman and Self Identifying as a
Sexual Being”

IRB#:10Jun09

The IRB has deemed that the research and procedures are compliant with the University of New Orleans and federal guidelines. The above referenced human subjects protocol has been reviewed and approved using expedited procedures (under 45 CFR 46.116(a) categories 6&7).

Approval is only valid for one year from the approval date. Any changes to the procedures or protocols must be reviewed and approved by the IRB prior to implementation. Use the IRB number listed on this letter in all future correspondence regarding this proposal.

If an adverse, unforeseen event occurs (e.g., physical, social, or emotional harm), you are required to inform the IRB as soon as possible after the event.

Best wishes on your project!

Sincerely,

Robert D. Laird, Chair

UNO Committee for the Protection of Human Subjects in Research

Vita

Ashley Volion was born in Louisiana in 1984. She received her undergraduate degree from the University of New Orleans in 2007. She began pursuing her Masters degree of Arts in Sociology in January 2008 where she has worked as a graduate assistant. She plans on pursuing her Ph.D. in Disability Studies in the near future.