

Managing Unruly Bodies: Public Policy and Disability Sexuality
Bethany Stevens, J.D., M.A.
Center of Excellence for Sexual Health Scholar
Morehouse School of Medicine

Abstract: Public policy that regulates and shapes the sexual and social lives of people with disabilities is focused on limiting freedom and agency. While analyzing the ideological underpinnings of such policy, the author also elucidates policy recommendations and ways that the field of disability studies can ameliorate the sexual status of people with disabilities.

Key Words: disability, sexuality, public policy

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Introduction

People with disabilities in the United States have historically been subjected to egregious forms of segregation and social devaluing. According to the disability section of the American Civil Liberties Union website:

“People with disabilities are still, far too often, treated as second class citizens, shunned and segregated by physical barriers and social stereotypes. They are discriminated against in employment, schools, and housing, robbed of their personal autonomy, sometimes even hidden away and forgotten by the larger society. Many people with disabilities continue to be excluded from the American dream” (2008).

Public policy regulating and shaping the lives of Americans often reflect the social status of people with disabilities through framing us as individuals who lack agency and therefore, need nondisabled people to step into our lives and control various aspects of it. This article seeks to not only criticize this dominant view of disability and query exactly how public policy does and could shape the sexual lives of people with disabilities, but also serves as a potential guide to shape the subject matter of a disability studies public policy course focused on sexual issues.

Analyzing public policy through a disability studies lens reveals that its focus historically has been a product of the dominant medical model of disability because it enforces the notion that people with disabilities are non-agentic and need protection. Further, public policy regulates the sexual lives of people with disabilities to advance the eugenic agenda of preventing the propagation of our unruly bodies. While disability studies attempts to promulgate the notion that disability should be celebrated rather than shunned, public policy regulating the sexual lives of people with disabilities continues to depend on the notion of disability as a deviation from normalcy thus, necessitating intervention. People with disabilities do often deviate from normative bodily movement and ability thereby often provoking hostility and fear within many nondisabled people. Historically, many types of bodies that provoke anxiety, such as those that are of color or queer, tend to be intensely regulated in the public policy realm with the guise of protection at work (Shildrick, 2007). A disability studies public policy course focused on sexual

issues would thus begin by positing the foundation of policy regulating our sexual lives within a sociopolitical context, as well as examine the historical underpinnings of that context.

The Perceived Policy Solutions to Manage Disability

Although rarely spoken of in the United States, there was once a pervasive eugenics movement attempting to make the population of United States somehow more pure – and certainly more able. The United States had compulsorily sterilization initiatives to manage the reproductive rights of certain classes of people – namely individuals with intellectual and/or physical disabilities – nearly a decade before the Nazis started 4 Tiergartenstraße (Black, 2003). Sterilization legislation gained widespread popular support in the 1920s. In 1933, Germany promulgated eugenics legislation based on legislation written in America. It is striking the extent to which Americans condemn Germany for its Nazi era methods of racial purification, yet rarely, if ever, discuss the fact that the United States was first to utilize the method of eugenics. Although, it is important to note that the Nazis annihilated millions of individuals, whereas the United States sterilized rather than killed individuals.

Until the mid-1970s in the United States, people who were mentally or physically disabled or ill, deaf, blind, epileptic, or physically deformed were targeted by compulsory sterilization legislation in thirty-three states (Lombardo, 1982). That legislation targeted many people with disabilities with the intent of eliminating defectives from the gene pool, in order to facilitate a better - more able - populace. In the Supreme Court case, *Buck v. Bell*, a student of eugenics Justice Oliver Wendell Holmes, Jr. (1927) wrote:

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

The only aspect of the holding in *Buck v. Bell* (1927) that has been deemed unconstitutional is that concerning the punitive sterilization of criminal individuals, whereas the sterilization of people with disabilities continues to be held constitutional (Lombardo, 1985).

While one might hope that this sort of archaic understanding of the sexuality of people with disabilities has subsided around the world, unfortunately this is not the case. There are current examples of compulsory sterilization around the world. But it is beyond the purpose and scope of this paper to include an exhaustive list of those countries that deploy this method to manage the sexuality of people with disabilities. The national government of Australia recently adopted the *Children with Intellectual Disabilities (Regulation of Sterilization) Bill 2006* authorizing forced sterilization (Frohman, 2007). In November of 2006, American Drs. Daniel F. Gunther and Douglas S. Diekema wrote in the *Archives of Pediatrics and Adolescent Medicine* about a controversial and legal procedure in which a severely intellectually and physically disabled six year old girl was given high levels of estrogen, underwent a hysterectomy and an appendectomy, and had her breast buds removed in order to stunt her growth and

reproductive ability (MSNBC, 2006). The treatment also rendered the child unable to menstruate as she aged, effectively to keep her from entering puberty. The rationale behind the treatment:

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

The authors of the article assert that the treatment is “both ethical and feasible and should be an option available to parents.” This case reflects the perceived lack of ethical issues related to the suppression of the sexuality of people with disabilities. Compulsory sterilization is an example of how public policy and general social perception permits if not encourages the treatment of people with disabilities as if we lack agency, both socially and sexually, thus coinciding with the medical view of disability. A disability studies public policy course focused on sexual issues would query how stripping someone of one of the fundamental aspects of personhood, sexuality, could ever be deemed reasonable if society did not view people with disabilities as non-agentic and asexual?

A pervasive solution to the “disability problem,” although not a final solution, is the use of nursing homes to house unruly disabled bodies. Today, there are over two million disabled people warehoused in nursing homes; where disabled bodies are actually worth more to the Gross Domestic Product than at home (Russell, 1998). According to Russell (1998), the average person housed in an institution or nursing home is worth around \$40,000 each year to the service providers in control of the nursing home industry; a figure that does not include add-on billings such as medication, or inflationary increases in resident fees. This proposed disability studies course would challenge the commodification and segregation of people with disabilities, as well as critique an industry that not only turns a profit on our bodies, but also keep us hidden away from the socionormative populace. Thus, alleviating any potential discomfort with our deviant bodies (Susman, 1994).

Nursing homes serve as a powerful force in the social and sexual suppression of people with disabilities. In nursing homes, all aspects of a persons’ agency are completely removed from their power and they are effectively rendered objects to be stored and profited upon. A particularly offensive component of this aspect of oppression for many people with disabilities is that while institutionalized people with disabilities are in some cases permitted to marry, they are not permitted to engage in consensual sexual acts (Finger, 1992). Further, in the few situations where heterosexual sexual relations are deemed permissible, homosexual activity is often prohibited (Finger, 1992). And to move beyond coupled sexual acts, there are countless instances of physical and psychological abuse exacted on people with disabilities if they engage in masturbation (Silverberg, 2006).

Another example of the felt need to suppress the sexuality of people with disabilities was noted in the recently ratified *United Nations Convention on the Rights of Persons with Disabilities*. In the arduous process of debating each word of the international human rights instrument, twenty-six countries, including the United States, refused the inclusion of an article explicitly dealing with various aspects of reproductive and sexual rights of people with

disabilities (Adams-Spink, 2006). As a result of the labored debate, sexuality is only mentioned in Article 25(a) briefly under the purview of access to healthcare. The more extensive article concerning sexuality could have been socially ameliorative to people with disabilities globally through recognition of the numerous facets of our sexual lives.

The argument to catalyze the noninclusion of the sexuality article in the convention was based on the tactic of conflating disability into one category (Shildrick, 2007). Disabilities, like queer sexualities, come in a multitude of manifestations – with disability comprising impairments ranging from physical to sensory impairments. Many people who advocate for the rights of people with disabilities continue not to know how to deal with the sexual lives of individuals with cognitive impairments. The main impediment in resolving the question of the sexual rights of people with cognitive impairments is the understanding of individuals with reduced mental capacity as lacking capacity to consent. The focus on issues of informed consent of people with cognitive disabilities obscure the situations of people with different forms of disabilities, thus conflating the spectrum of disabilities into one category of people who lack the capacity to consent to any sexual act. Therefore, on an international level, people who possess an impairment that does not affect mental capacity still lack the capacity to consent to any sexual act.

In many ways, the creation of this document is a progressive step for international law concerning people with disabilities, as it is recognition of the lack of access to fundamental human rights for the majority of people with disabilities around the world. Former United Nations Secretary General Kofi Annan stated that the convention offers a promise of “a way forward to ensure that those with disabilities enjoy the same human rights as everyone else -- in education, employment, access to buildings and other facilities, and access to justice” (Annan, 2006). But along with the promise of much needed progress, this convention is also an implicit codification of oppression because of its lack of an article dealing exclusively with sexual and reproductive rights. Instead of providing a path of sexual amelioration for people with disabilities, this convention silently supports the perception that many people with disabilities lack sexual agency and should be treated accordingly.

The Façade of Benevolence in Public Policy

These examples could be seen in the manner to which many individuals in applied fields studying disability frame them – as a manifestation of benevolence because people with disabilities need protection. According to this line of thinking, we need protection from ourselves and from nondisabled people who desire to prey upon our vulnerable nature. This statement is not intended to deny that many people with disabilities face physical and sexual abuse. People with disabilities comprise the highest risk community of people to face abuse globally (Light, 2003). Many groups of people, such as women and children, need government intervention to prevent their abuse, but the framing of policy as a benevolent act directly contradicts the values of disability studies because it politically disempowers people with disabilities by continuing to posit us as people who need someone to serve as our advocates, representatives or keepers (Cocca, 2002; Bevacqua & Baker, 2004). Further, the belief that this sort of action is benevolent assuages people’s guilt when they treat people with disabilities as though we lack fundamental

human needs and desires or social and political agency. I refuse to see these examples of policy as acts of benevolence and, rather, see them as forms of “erotophobia” (Wilkerson, 2002, p. 40).

Erotophobia manifests through the imposition of social taboos and constructs on certain classes of people in order to limit their sexual agency. This form of segregation is imbued with the medical ideology from which disability studies seeks to distance itself. This view is not only apparent in the social understanding of people with disabilities, but can also be seen as a force guiding policy and public perception of other devalued citizens, such as queer people. As Rubin (1999) assert, sex is a vector of oppression that “cuts across other modes of social inequality, sorting out individuals and groups according to its own intrinsic dynamics” (p. 160). Marginalizing people based on their sexuality is a powerful tool of social oppression and historically has been used to constrain the political and social agency of various groups of social dissidents and those regarded as “others,” such as queer, Black, and female individuals. Sexual stereotyping and other sexual harms, like imposing sexual shame on people through social oppression, are significant forces in perpetuating inequality of any oppressed group (Wilkerson, 2002). While one can argue that these social structures, such as that disseminating sexual shame associated with any particular identity, should not be viewed as a form of public policy, I contend that public policy is informed by and reinforces these public perceptions.

The Media’s Promotion of Oppressive Disability Narratives and Policies

A disability studies public policy course focused on sexual issues would need to examine the role of the media as a form of public policy. By analyzing its power to construct, define, and perpetuate the value of people with disabilities. The media shapes our sexual subjectivities as much as public policy itself has the capacity to regulate (Brown, 2002). For the most part, disability is ignored by the media. But when people with disabilities are represented in large, commercial media, it is typically in a stereotypical manner, thus enforcing the medical model of disability. The dominant narratives of disability, including the “pathetic cripp” and the “supercrip,” are pervasive in media representation and thereby, transmit into widely accepted supercultural notions (Susman, 1994). These narratives of disability are imbued with the history of eugenics and freak shows. The eugenic view of people with disabilities as *useless eaters* (Nazi terminology) and breeders can be noted in representations of disability that entail a person being posited as childlike, helpless, weak, and essentially worthless (Shildrick, 2007). One example is the Jerry Lewis Telethon, devoted to raising money for the pathetic crips with Muscular Dystrophy. It is fascinating that what the pathetic cripp really needs to be ameliorated is money.

The super-crip narrative is what one might think of when examining media representation of disability, as it is fairly commonplace within news stories, as well as sensationalized fictional depictions of disability. This entails a person with a disability who overachieves and is capable of just about everything without a drop of sweat and a perpetual smile. This narrative is imbued with the history of freak shows because it constructs physical and psychological distance between the nondisabled and the disabled person by exalting people with disabilities for engaging in simple acts. For example, both a person on a freak show stage and a person in a typical human interest story have been appreciated for playing the piano while being disabled (Larsen & Haller, 2002).

The media has a history of “representation and treatment of certain sexual practices and desires as disabilities and illnesses [through which disability is denied positive access to media representation] loudly, repeatedly and not silently” (Kafer, 2003, p. 85). The social reality of living with a disability can prove to be challenging, often offensive, and remarkably disempowering and exclusionary from many cultural contexts, such as public policy. This is why there are disability scholars and activists to raise awareness of how so many people with disabilities are denied access to the fundamental rights, privileges, and responsibilities of human life and citizenship. The profoundly sad glimpse into the reality of the lives of people with disabilities, I present here makes me wonder, “What is to be done?” I counsel that disability studies needs to engage with sexual radicalism and catalyze dissemination of disability culture into the mainstream as social solutions to subvert the dominant medical discourse of disability.

Paths to Ameliorate the Sociosexual Status of Disability

I concur with Rubin’s (1999) assertion that there is an urgent need for a radical theory of sex to overturn the problems with sexuality, including the hierarchies of sexual value and ability. Her conception of a radical theory of sexuality must “identify, describe, and denounce erotic injustice and sexual oppression” (p. 148). For people with disabilities, a radical theory of sexuality in action would entail denouncing the popular images and policy codifications that define our lives. We need to subvert the negative images of disabilities and replace them with images that claim our beauty, difference, humanity, and sexuality in a way that is public and proud. The next step must be changing popular conceptions of disability, such that public policy can reflect this shift. Claiming disability culture and disseminating it into the mainstream is a powerful tool to challenge the dominant view of disability as socially devalued. Work by the unrelated Berkeley performance artists Frank Moore and Leroy Moore¹, as well as other artists with disabilities, should be made more accessible to a larger scope of people. The images defining disability that pervade our culture must be countered with those that display our nuances and humanity. Through changing the cultural imagination about the status and meaning of disability, culture and thereby, public policy will shift to reflect this positive understanding.

The field of disability studies offers a valuable path to challenge the dominant images and social understandings of disability, thus ameliorating people with disabilities and temporarily nondisabled people as well. Statistics show that the majority of people will become disabled at some point in their lives – about eighty percent of people in the United States alone (Russell, 1998, p. Index). According to the United Nations fact sheet on disability, if a person lives to be seventy years old, they will experience disability for at least eight years or eleven and half percent of their lives (United Nations, 2006). That statistic does not take into account all the individuals who acquire disability through accident or illness earlier in life. Disability issues are not just the issues for people who are similarly situated to my (disabled) embodiment, rather they are everyone’s issues. As the subject of an Academy Award winning film, O’Brien, stated, “Everyone eventually becomes disabled, unless they die first. How much more natural can you get?” (as cited in, Aquilera, 2001). The public policy focus on disability as an issue framed as one of limiting our sexual freedom does not just affect people who live in disabled bodies currently. Instead, it has the potential to affect everyone. That is what is so unique about disability, as it is an oppression status that anyone at anytime might acquire.

People with disabilities contend with an intersection of oppression concerning impairment and sexuality, as American society generally has anxiety around talking about sexuality in a healthy way, as well as apprehension in discussing disability. If adding other aspects of intersectionality that catalyze fear and thus silence, such as queer sexualities and genders, racial and ethnic minorities, class and immigration status, the problem of sexuality becomes even more egregious for policy makers. But, this realization provides more support for more sexuality activists and scholars to be aware of disability and other intersectional issues related to sexuality. Finger (1992) said it best when she wrote:

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

Her quote is a call to action to initiate a revolution between our legs and our ears. This revolution can start to come to fruition is by analyzing how public policy might aid people with disabilities in accessing positive sexual lives. There are numerous actions currently in progress among of people with disabilities that work to enhance or help create our sexual lives, including facilitated sex, the use of sex surrogates, and the use of sex workers. This list is neither exhaustive, nor should creative policy makers stop with these suggestions alone. Additionally, disability scholars should take on the task of attempting to create solutions that address and ameliorate the sexual status of people with disabilities. A disability studies public policy course focused on sexual issues would need to start this process by engaging with these suggested methods of challenging the problems people with disabilities face in their sexual lives.

Facilitated sex involves the use of a personal care attendant providing a person with a disability sexual assistance, ranging from undressing a person prior to the sexual act to actually helping assist the individual in masturbation. This aspect of sexual access is quite controversial within both the disability community and the community of personal care attendants. Currently, this issue has no real codification dealing with the legality of these services or whether they are compulsory for personal care attendants (Shildrick, 2007). Despite the controversy around this issue, many people do have access to this form of assistance and do not view it as a form of sex work. Instead, they believe that facilitated sex is a means of garnering aid for a basic life activity, similar to requiring aid to bathe for example (Earle, 2001).

An issue that few people consider as a sexual outlet for people with disabilities is the use of sex surrogates. Sex surrogates work to “enhance a set of foundation skills which help to develop a positive, healthy sexuality” (Poezl, 2001, p. 126) using means such as breathing, relaxation techniques, erotic touching exercises, and teaching effective communication skills. Interestingly, many people think of sex surrogates as analogous to prostitutes because they do, in some cases, engage in sexual acts with their clients. However, to date there is no case law regarding this subject and it remains perfectly legal (International Professional Surrogates Association, n.d.). While there has been no comprehensive empirical study concerning the effectiveness of sex surrogacy, anecdotal evidence suggests that this form of therapy is rather successful, especially for late-life virgins and those who have been excluded from accessing sexuality (Society for Human Sexuality, n.d.).

The use of sex workers has recently gained momentum in the media as a means of aiding people with disabilities in accessing sexual lives, especially on an international level (Rohrer, 2007). In Australia, sex workers are trained to deal with the sexual and physical abilities of people with disabilities and many sex workers work in accessible brothels (Life Site News, 2005). Denmark and the Netherlands are taking similar steps in providing people with disabilities access to sex workers, and in some cases, actually providing a government subsidy to pay for the services (Shildrick, 2007). Both the use of sex surrogates and sex workers can be viewed as problematic. First, these services generally, if not exclusively, are used to serve men only (Rohrer, 2007). Second, providing sexual services on a paid basis reifies the notion that people with disabilities cannot procure sexual acts through our own volition. I find these aspects troubling but some men with disabilities find sex work to be incredibly freeing. One such individual, Asta Philpot, stated that after procuring sex work he “feels more confident with girls. I’m totally for it. Not one regret. Disabled people are so sheltered and protected, in an institutionalized force field” (as cited in Rohrer, 2007).

It would be beneficial if the United States would follow the lead of these countries and allow individuals of all abilities to seek sex work in a healthy and safe manner, thus supporting the human rights of both the client and the sex worker. But until those changes come to fruition, it is important for disability scholars and those who draft policy concerning the sexual lives of citizens in the United States (and beyond) to consider the issues of people with disabilities as important issues of our society. A disability studies public course focused on sexual issues would be a great point of departure to begin analyzing these issues in a collective way, as well as disseminate these ideas to people who might otherwise not engage with them. The recommendations I have offered for aiding people with disabilities in achieving a positive sexual life answer the question of whether sexuality is a human right and who is human enough to access that right.

Bethany Stevens, J.D., M.A., is a sexual health scholar in the Center of Excellence for Sexual Health at Morehouse College of Medicine. She is a member of the California Bar Association and a recent graduate of San Francisco State University’s Sexuality Studies graduate program. Additionally, she is a self-identified uppity crip activist. Please contact the author via e-mail at bethany.stevens@gmail.com or by regular mail at 2025 Peachtree Rd NE #332, Atlanta, GA 30309.

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Endnotes

- ¹ Leroy Moore is a writer, advocate and journalist on issues related to disabled people and individuals of color. For more information, please check out: <http://www.future-link.com/407LEROYFMOOREJR.HTML>. Frank Moore is a performance artist and television personality. For more information, please check out: <http://www.eroeplay.com/>

