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A Research Study on Individuals with Disabilities in the Maasai Tribe of Tanzania

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Abstract: The purpose of this qualitative study was to investigate the life of individuals with a disability in the Maasai Tribe in Tanzania. The study consisted of 68 participants. Individuals with a disability did not engage in tribal traditions, go to school or seek modern health care.

Key Words: Tanzania, Maasai, disability

Editor's Note: This article was anonymously peer reviewed.

The Maasai, of all African tribes, have always held a certain mystique. The Western World has referred to them as "noble savages" (Thomson, 1885) admiring their offensive warrior skills, aggressive cattle raids, and semi-nomadic lifestyle. Men wearing red tartan shukas carrying wooden staffs and women with shorn heads and huge disc necklaces proudly drift across the plains herding cattle. They are a close knit group, politically and economically isolated from mainstream Tanzania. In spite of pressures from the government, missionaries, and society in general, they have remained true to their pastoralist way of life. Cattle are still considered sacred and their lives are spent migrating (Maasai Association, n.d.).

The Maasai society is based on a patriarchal system, where men enjoy absolute power and women are considered dependents throughout their lifespan. Women are not allowed to speak in front of men, girls are viewed as financial assets when arranging marriages, and polygamy is the norm. It is not uncommon for a man to know exactly how many cattle he owns, but have no idea how many children he has fathered (Spear & Waller, 1993).

Their unconventional lifestyle and independent spirit have often brought disdain and bigotry from other tribes. Laws to protect the Maasai are often ignored and not enforced. For instance, laws were established to allow them cattle migration rights to Ngorongoro Crater, a wilderness area. But the Maasai have virtually been banned from the area, threatening their survival during the dry season (Maasai Association, n.d.).

Life for a Maasai with a disability is particularly problematic. Throughout history there has been a practice of killing and hiding mentally and physically impaired people. The Alaskan Inuits, the Woggeo of New Guinea, and the Massai Tribe of Africa have routinely rid themselves of what they considered to be a burden to their community (Davis, 1995). Whether it was death, sterilization, or limitations in jobs and education, the individual with a disability has faced and still faces prejudice and discrimination.

The number of individuals with a disability throughout the world is often underestimated. It is believed that at least one person out of ten has some type of disability (Kereto, 2007). The 2000 Population and Housing Census in Tanzania affirms these figures, reporting that 10% of Tanzanians had a disability. The most prevalent forms of disability in Tanzania were physical (28%), visual (27%), hearing (20%), intellectual (8%), multiple impairments (4%), and other (13%) (Kapuya, 2004). Unfortunately, the census is the only source of information about the number and types of disabilities in Tanzania (United Nations, 2001). In fact, almost all of Africa is void of any research concerning individuals with a disability as evidenced by the following statement by Arne H. Eide, "There is little data on disability in low-income countries in general. A few overview articles describe existing data as suffering from poor quality, lack of comparability and limited applicability. Disability statistics in low-income countries has so far largely comprised of impairment based prevalence figures" (Eide & Loeb, 2005, p. 2).

One of the rare studies conducted on individuals with a disability in Africa was done by Elly Macha (Hershey, 2001). She researched the impact of disability, gender, and access to education in Tanzania, focusing primarily on visually impaired women. She discovered that German measles was the main culprit in causing blindness: children were not being inoculated against the disease. The reason for the lack of inoculation was not neglect or ignorance; it was the distance needed to travel for health care. Currently, the majority of individuals with a disability live in rural areas making all types of health care, including inoculations, difficult to access (Mandesi, 2006).

Macha (Hershey, 2001) also found that individuals with a disability faced economic and educational barriers. It was particularly difficult for them to acquire start up money. Banks refused loans to them, considering them poor risks due to their lack of collateral. The lack of capital made it impossible for them to purchase land or open a business. They were also often denied education. Sometimes this was due to a lack of transport from their homes to the school, and other times it was due to a lack of properly equipped schools for children with special needs. In fairness, education is an issue for all Tanzanian children, not just individuals with a disability.

Tanzania has created legislation to guard and protect individuals with a disability, but it is rarely enforced (Kapuya, 2004). A plea from Reginald Mengi, Chair of Person with Disability Trust Fund, reflected the frustration of those with a disability when he said, "They are tortured, humiliated, kept indoors, shame to family" (2001, p. 1).There are also periodic reports of parents killing their children with a disability.

Methodology

The purpose of this qualitative study was to investigate the life of individuals with a disability in the Maasai Tribe from the Mondouli District of Tanzania. The Mondouli district was chosen because of the abundance of Maasai residing in the area and the location of a rehabilitation center for individuals with a disability in the district. A Research Permit from the Regional Administrative Secretary Arusha, The United Republic of Tanzania, Prime Minister's Office was obtained. Government officials from each district accompanied the researchers to every village to ensure credibility and to eliminate fear, as the lead researcher was white. Everyone on the research team was Tanzanian, except one American. It was believed that the prevalence of Tanzanians involved in the study was a strength and increased the ability to get a more accurate and honest account from the participants. Amina Mollel, a Maasai woman, led the interviews.

Individual interviews were conducted with persons with a disability, their family members, and the Director of the Center for Rehabilitation in the district. Participants from all three wards in the Mondouli district, Simanjiro, Makyuni, and Manyara, were included in the study. Purposeful sampling was done in order to target villages with individuals with a disability in their community. Government officials were particularly helpful in identifying the participants. All participants were Maasai. The study consisted of 68 participants with and without disabilities; there were twenty-one individual interviews and five focus groups. All participants were living in a subsistent manner, raising cattle. Only one person with a disability had graduated from primary school. The majority of family and community members without a disability had attended primary school; 28 had graduated from primary school. The Director of the Center for Rehabilitation had graduated from Form 4, not yet achieving a secondary school diploma. Her standard of living would be considered middle class in Tanzania.

Participants with a disability included nine individuals with physical disabilities, two with intellectual disabilities, one person with a visual disability, and two individuals with multiple disabilities. Of the fourteen individuals with a disability, nine were male and five were female. Age was difficult to determine, as the majority of people admitted they did not know their age. A few offered an age, for instance, one elderly woman said she was 35 years old, although she clearly was not. Therefore, approximations were used to determine age. Three of the males and three of the females were between the ages of seven and ten, four males were older teenagers, two men and two women were middle aged, and one man was elderly.

Family members of individuals with a disability, as well as community members participated in the study. All family members ranged in age between 25 and 65. One wife, two mothers, one grandmother, and three fathers were individually interviewed. Focus groups were used to interview community members. The Director of the Center for Rehabilitation was a middle-aged woman. Community members were adults ranging in age from 25 – 65 years old. The gender composition of the focus groups follows: Group 1 consisted of eight women, Group 2 had ten men, Group 3 had seven women, Group 4 had twelve men, and Group 5 had ten men. A modified form of convenience sampling was used to select members from the community. Leaders in each village, along with interested individuals, gathered to comprise the groups. The researcher had no power over the establishment of the groups; instead the chief in each village wielded absolute power.

The interviews were semi-structured centering on the following themes: perceived cause of disability, family and community attitudes and treatment of individuals with a disability, and health and government assistance. Before interviews began, traditional greetings were exchanged at each village to create a positive atmosphere. Time was spent explaining to the community elders, the family members, and the individual with a disability the purpose of the visit. This was done to increase the comfort level among all involved. Each interview lasted approximately one to two hours and was held in homes or on the plains. Interviews were conducted in either KiMaa or Kiswahili depending on the language preference of the participant. In most cases this was a very challenging enterprise as a question would be asked in English, then translated to Kiswahili and then finally into KiMaa. Responses were handled in a reverse order. Interviews were sensitive to cultural practices such as women not being allowed to stand or speak in front of men, wearing modest clothing and waiting for formal introductions.

Content analysis of the data consisted of coding for themes from each interview, organizing and summarizing experiences by theme, and then locating pertinent quotes. During the data collection and analysis the researcher synthesized and reflected upon the interview responses.

Findings

Among the Maasai there was a strong belief that a disability is caused by a negative supernatural experience. The lack of accurate information on the causes of disabilities puts the individual with a disability at a distinct disadvantage and makes it easy for others to justify discrimination.

Myths

Three explanations were consistently given for the cause of a disability; curses, witches, and God's will. Curses were attributed to shameful or harmful behavior on the part of the mother, father, or grandparent of the individual with a disability. Examples that were given included, "did not give food when there was famine," and "did not let children sleep safely inside the house." A child with a disability brought shame upon a family because it made the entire village aware of their disgrace. A curse could then also bring bad luck to the family. A man told the story of a family with three boys, “Two boys were born strong and one was small [referring to his disability]. The two strong sons died, the weak son took his brothers’ blood and so a bad omen.” Disabilities that occurred at birth were usually blamed upon a curse. If the disability persisted, it was then blamed on a witch. As one man said, “It’s two phases.”

Often disabilities that occurred later in life were blamed on a witch. One man believed his paralysis was due to being bewitched. He explained his disability in the following way, “My neighbor stole my cattle. I went to fight him to get my cattle back and when fighting to get them back my neighbor bewitched me. That is why I cannot move one side of my body.” He then explained how he went to many traditional healers (witch doctors) and “they all confirmed it was a witch that had caused my paralysis.” One grandmother said, “We took her to witch doctor when saw she was disabled. Thought problem could be cured, got a medicine there [it did not work] and leave her alone now.”

The third explanation for a disability was God’s will. It is speculated by the researcher that many individuals in the tribe believed this was the desired answer by outsiders. During the focus groups when one person responded with this answer, all others parroted the response. This was true even when they had previously stated that a curse or witch was the cause of the disability.

Their Fate

Only a few participants believed that the Maasai continued to kill individuals with a disability--instead most vigorously protested the possibility. They all acknowledged that it had happened in the past, but as one said, “The last 15 years brought change.” Only one person said he believed people with disabilities were still killed but in a more secretive manner. A few said that killing them was a sin, but that it was okay to neglect them by not feeding them or abandoning them. This was evidenced by some of the children in the rehabilitation center. According to the Director of the Center for Rehabilitation, one boy who was blind was found alone in Ngorongoro crater. He had been left to die and was afraid to move due to the threat of wild animals. Another young girl was found in a deserted village with a small jug of water and some food.

There were notably fewer individuals with a disability the farther the participants resided from the city of Arusha. Maasai near Arusha tended to farm while those living farther from Arusha migrated with their cattle. An agrarian lifestyle reduced the problems associated with caring for an individual with a disability. The difficulties of migrating with a person with a disability came up in every interview. One woman said, “They can’t walk, need a donkey which is not always safe.” Another said, “We hide them in the house and leave them when we migrate.” It could be speculated that the further from civilization the more likely the Maasai were to resort to primitive practices of hiding or killing their community members with a disability. Interestingly, the words “hide” and “kill” are used interchangeably in KiMaa.

While neglect, hiding, and killing may still happen in the Maasai tribe it was clear that many did not approve of the practice. Almost all realized it was not accepted by Tanzanian society.

Perceptions and Involvement in Community

Most individuals with a disability did not feel they were a part of their community. Lack of acceptance by their tribe was attributed to their inability to be a contributing member. As one woman said, “Disabled is a person who can’t work.” If you cannot work, if you cannot migrate with your people, if you cannot be educated then you are a liability, not an asset to the community.

When asked about support from family and community, the one constant response was that they received sole support from their mothers.

As one boy said, "It's just me and my mom." Most felt that members of their community ignored them or made fun of them. They were usually not able to keep up with their age-mates, something that is very important in the Maasai culture. A 16 or 17 year old boy said, "I want community to see me like a human being. I am always considered a young boy." Another said, "You are looked like as a burden, because no money, no school. I'm not allowed to do any tribal activities." One woman said she was not accepted at first in her community, but then, "a priest told them it could be them and they stopped laughing at me." The power of a respected and influential person made a difference in this situation.

As is the custom, throughout the interview process women never spoke when men were present. One young woman began to share immediately after her father left the area. She had a slight disability, paralysis on one side of her upper body. She was married and had three children. She said, "I dig and fetch water with one hand and my children help me. I call on other women to help me do things, like renew my hut for the rainy season." She said when she was younger she was teased by the other women: "I never listened to their words – always just left." Another middle-aged man perceived himself to be valued by his community because he had graduated from primary school, which made him more educated than most of his peers. He was also able to walk with the aid of crutches and therefore was capable of some work. The severity of a disability and the degree to which the disability was considered a burden to the community seemed to influence the level of acceptance by the tribe.

The perspective of the elders was often different from the perspective of the individual with a disability. In one village the elders said, "We include him; we take him when we migrate." The teenager with a disability then emotionally spoke: "I get no help and am not considered part of the tribe. They leave me when they migrate." His father, concurred, saying, "He faced many difficulties because can do no work to provide for his needs."

Involvement in the community and tribal rituals by people with disabilities was usually minimal. Some of the males with a disability were allowed to go through the circumcision ceremony. After the ceremony, boys traditionally go into the wilderness for a couple of months as a survival test. Modifications were made for those with a disability; they were allowed to stay close to home and be protected. This led to an interesting discussion on female circumcision in one village. The elders all said the practice had been abolished, but when young married men were asked if their wives were circumcised, they laughed and all proudly said, "yes." Females responded that they wanted to be circumcised because it signified adulthood and if they did not participate in the ceremony it would mean no husband, no children, and they would be forbidden to take part in tribal rituals. These were all things they valued and wanted in their lives.

Only one person with a disability had received an education. Some did not want to go to school, saying, "Teachers were mean to me." A chief commented, "Head teachers don't want them because they don't have time." The distance to school was also usually cited as a reason that the individuals with a disability and others in the community were not educated.

Most men in the community said they would not marry a woman with a disability; the only exception was "if the disabled girl can give a baby." One girl talked about not being "beaded" when she was younger. Girls commonly receive a beaded bracelet from a man when they are about ten years old. This is regarded as a promise to protect and perhaps marry them. She believed her disability prevented her from being beaded. All participants believed it was not a problem for a woman to marry a man with a disability.

Health Care

None of the participants with a disability sought modern health care on a regular basis. Their proximity to the rehabilitation center and health services did not seem to make any difference in their decision to seek or not seek care. Of those who were taken to the rehabilitation center, they only went once, as one mother said, because they "could not be healed…didn't take him for more exercise because no one to help with other children."

It is possible that some parents desire a permanent placement outside the home for their child with a disability. There is no facility for long term shelter for individuals with a disability in the district. One chief became very angry when he realized the researchers would not take his daughter with severe multiple disabilities. In another village, the threat of being given away was seen in the actions of a young girl with a club foot. She became hysterical and tried to run away when she saw the research team approach, believing they had come to take her away.

An abundance of burn victims were in the rehabilitation center, and often their burns had been neglected for a year before they came to the center. The charcoal burners used for cooking were seen as the main culprit. Protective devices have been designed to reduce the incidence of burns, but none were seen being used in any of the villages that were visited.

When asked their greatest worry, participants' first response was that the government would take away their lifestyle: "We don't want government intruding on our lives." But at the same time there was a consensus of wanting more assistance from the government. Most believed they received "no help from the government." In essence, they wanted more help from the government, but at the same time feared their involvement.

Recommendations

Whether it is death, sterilization, or limitations in jobs and education, individuals with a disability face prejudice and discrimination in Tanzania. It is particularly problematic for Maasai with a disability.

There is an initial and immediate need for Outreach Programs that offer physical therapy and medical treatment for individuals with a disability in the Maasai Tribe. A combination of wariness toward modern medicine, distance from services, and other family duties make it unlikely that children with a disability will be taken to health services for initial treatment or rehabilitation. An Outreach Program, where trained professionals go to the villages, would be a good transition between receiving no care and seeking treatment.

There is also a need for education on the following issues: prenatal care, disabilities, other health care issues, and the proper use of cooking facilities to reduce burns. The involvement of both men and women in the education programs would strengthen their effectiveness. The patriarchal nature of the Maasai Tribe makes it imperative that men be included if change is to take place. Involvement of women is self-evident, since they are involved in most of the day to day care of the individual with a disability and all health issues.

In addition, there is a need for more rehabilitation facilities and extended living services for individuals with a disability. Currently, there is only one rehabilitation center in the district, with a capacity for 30 patients. Clinicians frequently find themselves serving 100 people and their patients find themselves sleeping in hallways or on the floor. In addition, there is a need for extended living services; currently none exist in the district. This is an important feature of a comprehensive program for individuals with a disability.

Finally, vocational training centers that not only train, but also offer employment opportunities, need to be provided. This would give the individuals with a disability the ability to support themselves and become productive members of society. Such programs are rare in Tanzania and tend to have long waiting lists.

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The Reasonableness of Working from Home in the Digital Age

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Abstract: The Americans with Disabilities Act states that employers must make "reasonable accommodations" to allow disabled employees to work effectively. Using summary statistics, a theoretical model and a legal history, this article will attempt to determine whether home-based work is a "reasonable accommodation" under this law.

Key Words: home-based work, reasonable accommodation, Americans with Disabilities Act

There are only two known photographs of Franklin Delano Roosevelt in his wheelchair (Franklin Delano Roosevelt, n.d.). During the time of his presidency, the common view in the medical profession was that disabled people could not be rehabilitated. Not surprisingly, "(a) ware of the stigma attached to physical disability, Franklin D. Roosevelt went to great lengths to hide his own [disability] so as not to shake the public's faith in his ability to lead the nation" (Gallagher, 1985, as cited in O'Brien, 2001, p. 21).

The world has changed drastically since Roosevelt's presidency. People living with disabilities have become more integrated into society and discrimination against them has decreased. The disability rights movement led to the Rehabilitation Act of 1973, but the act only applied to those in the public sector (U.S. Department of Labor, 2008). The Americans with Disabilities Act (ADA) (1990) followed. It was signed into law on July 26, 1990 and became effective two years later. The ADA expanded coverage, providing protection for those in both the private and the public sectors. Title I of the ADA addressed the employment situation of people with disabilities.

The ADA was enacted to mitigate the discrimination against people with disabilities and to help them participate in all aspects of life, including the workforce. Title I of the ADA[1] requires that employers take steps to accommodate disabled employees. If a disability impedes the ability of an employee to complete necessary job tasks, the ADA states that the employer must try to make changes or accommodations that would allow the employee to work effectively. There is still a tremendous lack of clarity among employers regarding both the scope of their responsibilities under this statute and the definitions of a "reasonable accommodation" (Ludgate, 1997, p. 1311). Employers can accommodate workers at the onsite workplace or by allowing them to work from home. Working at home goes against the traditional constructs of work, so it brings particular challenges to the development of a complete body of law that covers workers (Ludgate, 1997, p. 1313).

This article addresses two related topics. First, it outlines the legal history of home-based work as a prospective "reasonable accommodation" under the Americans with Disabilities Act. There has been much reticence to accept home-based work as a reasonable accommodation, but technological improvements are changing this viewpoint in society, if not in legal precedents. Second, through the use of summary statistics and a theoretical model, the article outlines the employment landscape for persons with disabilities before and after the passage of the ADA, illuminating the work-state of people with disabilities–out of the labor force or in, employee or self-employed, working from home or onsite. These two topics will be brought together to determine whether or not the "reasonable accommodation" mandate of the ADA coupled with technology improvements allows home-based work to become another avenue to increase the labor force participation of people with disabilities.

The Scope of the Americans with Disabilities Act

The ADA was enacted in order to reduce discrimination against people with disabilities and to bring these individuals into mainstream society (Ludgate, 1997, p. 1313). Title I of the ADA deals with employment discrimination, which is a key factor that contributes to economic hardship in the disabled community. The ADA protects "qualified individuals" with a disability. Title I of the ADA defines a qualified individual as an employee who "[either] with or without reasonable accommodation . . . can perform the essential functions of the employment position that such individual holds or desires" (42 U.S.C. § 12111(8), 1990). An individual's qualification is inextricably bound with the concept of reasonable accommodation (Ludgate, 1997, p. 1314).

The Interplay between Working from Home and the Goals of the ADA

Working at Home as a More Viable Option

The vast majority of employees commute in the morning to a workspace that is separate from their homes. However, strides in technology have allowed telecommuting to be a more viable option. Telecommuting became much more prevalent in the 1990s and continues to thrive. In fact, according to a Survey of Income and Program Participation study, in 1997, more than 6.4 million wage and salary workers worked exclusively from home (Kuenzi & Reschovsky, 2001).

The benefits of working from home for workers include increased flexibility and control, a reduction in time spent getting to work, and lower transportation costs. Working from home also has benefits for employers, including "savings on office overhead, lower employee absenteeism, increased productivity, improved employee morale, and higher employee retention" (Ludgate, 1997, pp.1322-1323). Despite all the benefits of working from home, there are a number of barriers that limit its expansion. For example, working at home is not a suitable option for jobs where face-to-face contact with the public or clients is necessary. For instance, a waiter could not feasibly work from home. Even in jobs that don't require "face time," working at home leads to management challenges, including performance monitoring and communication delays. However, the latter of these issues is declining as the power, speed, and prevalence of e-mail increases.

Even if telecommuting is appropriate for a specific job, it might not be suitable for every worker. Some people need constant supervision and cannot work independently in an effective way. Others may have the ability to work effectively at home, but prefer to work in the collegial atmosphere of an office. Some people believe that there are economies of scale in an office space – that the exchange of ideas lead to greater productivity because a problem can be figured out more quickly with more minds.

The *Vande Zande* Presumption against Working from Home – Is it Necessary to be Onsite?

Vande Zande v. Wisconsin Department of Administration is a Seventh Circuit case that addressed whether working from home is a reasonable accommodation under the ADA. It used a number of "excessive absenteeism" cases as a foundation from which to build. These cases evaluated whether serial absenteeism due to a disability is something that an employer must accommodate. The courts:

> ". . . Have held that disabled employees are not qualified for a position if they cannot maintain predictable attendance at work. Typically, these courts support this conclusion by noting the disruption caused to an entity's operations when

> an employee is not reliably present. . . . These declarations have formed the basis for a presumption, followed in some telecommuting cases, that because physical presence at work is an essential function of employment, telecommuting is almost by definition an inappropriate accommodation" (Ludgate, 1997, pp. 1324-1325).

Vande Zande stands for the proposition that working at home is almost never appropriate.

The presiding judge, Richard Posner, stated in his decision, "It would take a very extraordinary case for the employee to be able to create a triable issue of the employer's failure to allow the employee to work at home" (*Vande Zande v. Wisconsin Department of Administration*. (1995), p. 545). The court based this statement on the belief that most jobs take group effort, and having one of the team members away from the office would substantially lower the productivity of the group. In order to support this presumption, the court pointed to excessive absenteeism cases and held that in most cases an employer does not have to allow an employee to work from home.

Other courts followed *Vande Zande's* lead and presumed that working at home should only be appropriate in unusual cases.2 The outcomes of these cases were premised upon the assumption that consistent attendance is a fundamental job requirement. Even though some courts after *Vande Zande* took a fact-based approach and did not accept a blanket prohibition on home-based work, their decisions were framed by an assumption that working at home is not an appropriate accommodation.

Is the Presumption Against Home-Based Work Based on the Wrong Framework?

The presumption laid out in *Vande Zande* in evaluating the reasonableness of working at home lies on unstable ground (Ludgate, 1997, p. 1331). Judge Posner and the Seventh Circuit relied on excessive absenteeism cases when they said that physical presence was an essential function of the vast majority of jobs. Consequently, they virtually eliminated the possibility of working from home as a reasonable accommodation. Under this calculus, the home-based work option suffers from a wholesale prohibition. Thus, courts, in following the *Vande Zande* reasoning, have not needed to engage in fact-specific analysis (Ludgate, 1997, p. 1331).

Further, the court failed to explain how these excessive absenteeism cases were relevant in the telecommuting framework. In a typical excessive absenteeism case, "adequate job performance and physical presence at work are interrelated, either because the plaintiff's job cannot be performed off premises or because the plaintiff is unable to work with any regularity" (Ludgate, 1997, p. 1332). This assumption is different in the typical telecommuting case. In this area, the employees argue that physical presence is not a factor in performance. A fact-based approach must ensue to see if the employee actually can work productively at home. If we rely on the presumption that presence is essential, then the fact-based approach of the specific case is a moot point. While employers definitely need high quality performance from their employees, it is not at all clear that employers need their physical presence to engender it.

Is Working from Home Feasible?

The *Vande Zande* court also grounded its assumption against home-based work on the supposition that working at home significantly lowers productivity because of the inherent lack of supervision. A fact-based analysis is needed to determine the suitability of a specific person and a specific job to telecommuting. As detailed above, courts have generally underestimated the plausibility of working from home by declining to analyze beyond the blanket prohibition of home-based work (Ludgate, 1997, pp. 1332-1333).

Technology has grown with leaps and bounds in the past decade. Now fax machines, email, and conference calls are common features of life. This new environment allows people to meet deadlines and share ideas with their coworkers, regardless of their physical location. In the *Vande Zande* decision, Judge Posner recognized that the premise against working from home would weaken as technology advances but underestimated the technological framework already in existence:

> "*Vande Zande* was argued in 1994 and decided in January 1995, when companies like CompuServe and AOL were just starting to provide Internet access to large numbers of in-home users and Amazon.com began selling books online. Less than a year before *Vande Zande* was published, Vice President Al Gore first coined the phrase 'information superhighway' in a speech outlining the administration's support of the fledgling Internet and its commitment to revolutionary growth in an information technology industry" (Valenza, 2004).

Now, more than ten years later, technology has evolved and the feasibility of home-based work can no longer be denied.

The ADA's Reliance on the Case-by-Case Approach

The case-by-case approach in determining whether or not an accommodation is reasonable is not only correct, but also the approach mandated by the ADA (Ludgate, 1997, p. 1335). The ADA requires that courts must complete a fact-based analysis that takes into account the interests of both the employee and the employer. The presumption against working from home based on physical presence as an essential function goes against the requirement of a fact-based investigation of reasonableness. This presumption also disqualifies plaintiffs who need to work from home. They are in a catch-22 situation since physical presence is required to be qualified for a certain job and Title I of the ADA protects only "qualified individuals." Therefore, the presumption precludes the give and take of employer and employee in determining a reasonable accommodation. The "presence is essential" presumption allows the employer to refuse to examine the feasibility of setting up a telecommuting arrangement with the employee. Evan Kemp, a former commissioner of the EEOC, gave this frank explanation of disputes regarding reasonable accommodation: "[I]f [an employer] wants disabled people, the accommodations really don't become a burden. If they don't, they always do" (as cited in Valenza, 2004).

The presumption against home-based work belies the purpose of the ADA, which is to help bring disabled workers into the ranks of the employed. A work-from-home arrangement might be the only viable option for a person who cannot leave home on a regular basis. Excluding a whole category of accommodation from thoughtful deliberation seems to go against the tenets of the ADA. In fact, the EEOC code expressly states that the point of a fact-based framework is to expand the range of employment opportunities for disabled workers.

The Change in the Employment Landscape for the Disabled during the Dawn of the Americans with Disabilities Act

Was the world a more favorable place for those with disabilities in 2000 than in 1990? Were people with disabilities more likely to be working in 2000 than in 1990? If they were working, were they working at home or onsite? Did the option of home-based work facilitate their labor force participation?

In this article, the indication of disability is based on self-identification. This can lead to measurement issues as well as societal influences. That is, self-reporting could result in either an overstatement or understatement of true disability. It could overstate the number of the truly disabled if those without disabilities "identified" as disabled to get workplace accommodations or to justify being out of the labor force. On the other hand, it could understate the number of disabled individuals if the respondent feels stigmatized by accepting that identity. The passage of the ADA increased the visibility and societal acceptance of the disabled, but it also created a new protected class. Both of these factors could lead to an increase in the number of people who identify as having a disability, many of whom might not have the ability to work. In an article written for the Disability Statistics Center, Kaye (2003) writes, "Any increase in the proportion of the disability population who are unavailable to work could easily mask any gains made in employment opportunities for those who are available to work" (p. 15). We need to keep this in mind when looking at changes in labor force participation of people with disabilities after the ADA went into effect.

Another caveat is the possible unintended consequence of using a work-related disability measure. One consequence of the ADA is that, if it is effective in its goals to help integrate people with disabilities into the workplace, fewer people will identify themselves as being limited or unable to work. A person who formerly self-identified as having a work disability would be currently working and, thus, by definition, would no longer be able to answer affirmatively when asked if she is unable to work. Therefore, even though she needs accommodation to be able to work, she would not be counted as a person with a work-related disability in the Census results. This result would be misleading; it would appear that the work participation *of those currently disabled* had decreased. This change in disability status would lead to a kind of adverse selection bias where only those who are unable to work would be considered disabled. This scenario might lead to the false conclusion that the ADA had either no or a negative effect on the employment rates of people with disabilities (Schwochau & Blanck, 2003, p. 71).

The data used below come from the Integrated Public-Use Microdata Series of the Census (IPUMS) (Ruggles et al., 2004). The IPUMS data allows the respondent to identify herself as having a number of different disabilities. The 1990 and 2000 waves of the Census outlined three consistent categories of disabilities-- disabilities limiting work, disabilities limiting mobility and personal care limitations. If the respondent identified as being in any of these categories, he or she is considered to have a disability.

Table 1 outlines the employment landscape for people with disabilities in 1990 and 2000. It shows the number and percentage of people with disabilities in various work states and the changes in this environment during this decade. The Americans with Disabilities Act only covers employees. Those who are self-employed are not covered under the auspices of the ADA. All of the non-ADA changes of the 1990s affected the self-employed disabled in the same way as the disabled who were employees. Therefore, the self-employed can be used as a comparison group to see what effect the Americans with Disabilities Act had on the employment status of people with disabilities.

Summary Statistics

In 1990, there were 5,521,148 people in the United States who described themselves as having a disability, accounting for 8.1% of the population. More than half (3,204,010) of people with disabilities were onsite workers – approximately 50% as onsite employees and 8.4% as the onsite self-employed. Only 81,877 people with disabilities worked at home–0.5% as employees and 1% as self-employed. More than 40% of people with disabilities in 1990 were out of the labor force. This dearth of home-based workers could be the consequence of the lack of telecommuting resources and computing power at that time.

Persons with disabilities made up a large proportion of the out of the labor force population, with 25.2% identifying as disabled. Those who were working in 1990 were less likely to identify as having any sort of disability--5.2% of onsite employees, 8.4% of the onsite self-employed, 6% of home-based employees, and 5.2% of the home-based self-employed.

By contrast, in 2000, 7,515,761 people identified as being disabled, a 36.1% increase from 1990. The percentage of the population identifying as having a disability increased as well, rising to 11.3%. This is a bit higher than the figures in the Current Population Study, which showed "a significant 1 percentage point difference between the averages prior to and including 1991…and later" (Hotchkiss, 2003, p. 13). The increase in the number of people with disabilities may have been caused by an over-reporting of disability, which stemmed from the passage of the Americans with Disabilities Act. The difference in the scale of the increase suggested by the two datasets could come from the varying definitions of disability used, as discussed earlier.

According to the IPUMS data, between 1990 and 2000, both the employment status and worksite location of people with disabilities had undergone important changes. A greater number and percentage of people with disabilities were onsite employees and home-based employees and fewer were out of the labor force. Overall, the number of people with disabilities who were self-employed onsite or at home increased, but the percentage fell or stayed the same. In 2000, 76.8% of people with disabilities were onsite employees, 4.8% were self-employed onsite, 0.8% were home-based employees, 1.1% were self-employed at home, and the remaining 16.5% were out of the labor force.

There were 144,078 home-based workers and 6,134,703 onsite workers who identified as disabled in 2000. People with disabilities comprised 9.1% of home-based employees and 8.3% of the self-employed who worked at home. Those with disabilities made up 10.4% of onsite employees and 10.5% of the self-employed who worked onsite. Approximately one in five people who were out of the labor force in 2000 had a disability.

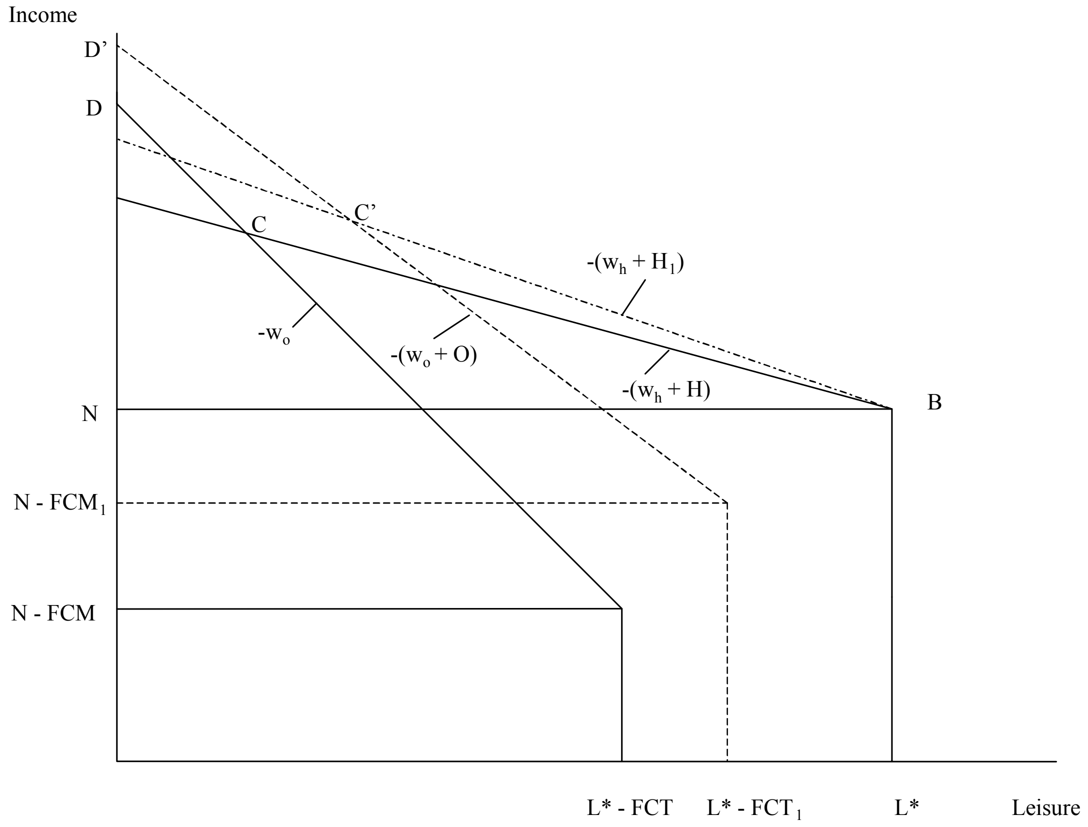
The number of people identifying as disabled rose almost 40% during this decade, but the number of people with disabilities who were employees increased by an even greater amount. Disabled home-based employees increased in numbers by 140% from 1990 to 2000, and those who were onsite employees increased by 110%. The number of home-based self-employed persons with disabilities increased as well, but in a more muted fashion. Persons with disabilities were less likely to be part of the onsite self-employed in 2000 than in 1990.

There was a drive for those with disabilities to go to work, regardless of worksite or self-employment status. Almost 3 million more disabled people worked in 2000 than in 1990 and almost 1 million fewer identified as being out of the labor force during that time. There was also an increase in the number of disabled people in the workforce who identified as having a disability that limited work. It seems like two things were happening during this period–people with disabilities who were out of the labor force in 1990 became employed either onsite or at home by 2000, and those who did not identify themselves as disabled in 1990 did so in 2000. The ADA may have had an influence on both of these factors.

The Theoretical Basis for Home-Based Work[3]

The theory behind the home-based work model presented in this paper is based on "Home-Based Work and Women's Labor Force Decisions" by Edwards and Field-Hendrey (2002), which in turn is based on previous work done by John Cogan on fixed costs and labor force decisions.

Figure 1: Diagrammatic Model of Labor Supply by Worksite, Before and After the ADA*



* Solid lines – pre-ADA, Dashed lines – post-ADA

Source: Edwards & Field-Hendrey (2002)

Edwards and Field-Hendrey outline two differences between onsite work and home-based work:

> "First, the fixed costs associated with working (e.g. time costs associated with commuting, out-of-pocket commuting expenditures and clothing costs) are greatly reduced for home-based workers. Second, home-based workers may be able to engage in some joint production of income and household 'commodities'" (Edwards & Field-Hendrey, 2002, p. 174).

Edwards and Field-Hendrey's analysis focuses on the labor force participation of married women. Since married women often do the majority of the child-rearing and household maintenance in heterosexual relationships, they have a different decision making process than men when considering whether or not to enter the labor force and for how many hours. Women have different reservation wages, the minimum wage level to induce a person into the market, and this reservation wage is dependent on many factors, including other income and presence of children in the family.

There are differences in the fixed costs of working onsite as opposed to working at home. In order to work at an onsite job, a person has to incur two different types of fixed costs – monetary and time costs. These costs may include buying work clothes, maintaining a car, buying gas, paying for parking, buying a bus pass and spending commuting time in the car or bus.

Fixed costs are not the only things that differ between these two work-states. There is also a different wage offer given to those who work at home as opposed to those who work onsite. If the wage offer were the same regardless of work-state, then the opportunity set for those who worked onsite would always fall inside the opportunity set of the home-based because of the lower fixed costs associated with working at home. Therefore, a person who had no preference between working at home or working onsite would always choose to work at home because she would be on a higher indifference curve.

But, data shows that the vast majority of people in the labor force work onsite. Therefore, the income that a person gets from wages must be higher for those who work onsite relative to those who work at home. Some of the reasons for this lower wage offer were outlined in the above section Working at Home as a More Viable Option. Monitoring difficulties, the lack of synergies of workers in the same space, the unsuitability of certain jobs for home-based work, and the belief that home-based workers are less productive than their onsite counterparts are all reasons why there is a lower demand by employers for home-based workers. This leads to a lower wage offer for home-based workers relative to onsite workers.

However, the wage is not the only good that a worker gets if she chooses to work from home. Edwards and Field-Hendrey allow for joint production of work and household "commodities" in the home-based work context. They assume that there is "some level of household production (such as child or elder care) per hour when one is doing home-based work" (2002, p. 176). Their model is illustrated in Figure 1. It is outlined as follows: N is unearned income, L* is total time available, FCM are the fixed monetary costs of working at an onsite workplace (e.g., commuting costs), FCT are the fixed time costs that are incurred when working on site (e.g., commuting time), Wh and Wo are the wage offers for home-based and onsite work, respectively, and H is the monetary value of household production per hour of home-based work. They assume that $Wh < Wo$ and that FCM and FCT are zero when working at home. Also, for simplicity, H is considered to be zero when a person is out of the labor force. The budget constraint is BCDL*. If a person ends up at point B, she is out of the labor force. If she ends up on the line segment BC, she is a home-based worker and if she is on the line segment CD, she works onsite.

Fixed costs play an important role when choosing worksites, as seen in Figure 1. As the monetary and time costs of working onsite rise, the line segment CD moves down and to the left. This means that a person will be less likely to be an onsite worker, choosing instead to be a home-based worker or out of the labor force. The importance of the value of joint production of household commodities, H, on work-state choice, is also shown in Figure 1. A higher value of H will increase the probability that a person enters the labor force as a home-based worker. An increase in H has the same effect as a higher value of Wh. Since the option of home-based work reduces many of the costs of working, Edwards and Field-Hendrey state that "the presence of the home-based work option leads some women who would have chosen to be out of the labor force to enter as a home-based worker" (2002, p. 176).

How Can We Expand This Model to Learn About the Work-State Choice of People With Disabilities?

The theoretical basis for worksite choice for people with disabilities can be derived from the Edwards and Field-Hendrey model. People with disabilities, too, have greater costs of working than their non-disabled counterparts, similar to the differences that Edwards and Field-Hendrey found between married men and women. There is a deterrent effect of disability on the probability of working; those with disabilities are more likely than their non-disabled counterparts to be out of the labor force. Lack of accommodation might be a factor leading to this reduced level of employment. Transportation, mobility and accommodation issues affect the disabled more than the non-disabled. Therefore, the fixed costs of working onsite may greatly influence persons with disabilities when deciding if and where to work.

Table 1: Number and percentage of people with disabilities, age 25-55, by workstate, 1990, 2000

	1990		2000	
	Number	Percentage**	Number	Percentage**
Total	5,521,148	8.1%	7,515,761	11.3%
Home-based employee	26,693	6.0%	63,704	9.1%
Home-based self-employed	55,184	5.2%	80,374	8.3%
Onsite employee	2,737,924	5.2%	5,772,462	10.4%
Onsite self-employed	466,086	8.4%	362,241	10.5%
Out of the labor force	2,235,261	25.2%	1,236,980	20.1%

** This shows which percentage of the given workstate has certain disabilities. For example, in 1990, 25.2% of those out of the labor force had some sort of disability

Just like the married women in Edwards and Field-Hendrey's model, persons with disabilities can jointly produce "household commodities" when working at home. In addition to commodities encountered by many women, such as child care, a household commodity for a person with a disability could be having a doctor's or therapy appointment, or taking care of oneself when symptoms flare up. Home-based work could provide the flexibility and lower costs of work that could induce those with disabilities to enter the labor force. This is the reason why the Edwards/Field Hendrey model fits when looking at the labor force participation choice of persons with disabilities.

The Effect of the ADA on Worksite Decision

The Americans with Disabilities Act affected the employment situation both directly and indirectly. Title I mandated that employers must reasonably accommodate their workers either in the onsite workplace or by allowing them to work at home. The onsite workplace changed as a result of this legislation – wheelchair ramps were built, new entrance exams were created, and flexible schedules were allowed. The home-based worksite did not change because of the ADA, however; it just was suggested as a more viable accommodation option. The actual home-based worksites looked the same as they did in 1990. The home-based worksite had always been an accommodating option for people with disabilities. Both before and after the ADA, those with disabilities could perform household commodities, H, while working at home. Working at home also eliminated the fixed monetary and time costs associated with working onsite, FCM and FCT, respectively.

The passage of the ADA made the onsite workplace more accommodating, although it was still not as accommodating as the home-based worksite. Figure1 shows this change. Title I of the ADA addresses the treatment and accommodation of persons with disabilities in the workplace. Title II of the ADA addresses public transportation issues, such as accessible buses, trains and stations. One of the effects of Title II on those with disabilities is that it lowers the fixed time and monetary costs of transportation to an onsite workplace. People with disabilities who want to work onsite now have more transit options, and therefore their total transit bill will decrease in both time and monetary terms. Those who choose to work onsite still incur fixed time and monetary costs to working–they still must get to work and that costs time and money–but FCT and FCM have decreased to FCT1 and FCM1, respectively.

There is another change for onsite workers with disabilities because of the implementation of the ADA. Title I requires that employers "reasonably accommodate" their workers. One such accommodation could be a flexible schedule in order to go to regular doctor's appointments. Therefore, after the onset of the ADA, onsite workers with disabilities are allowed to do some joint production of commodities, O, while at work. This benefit gets added to the onsite wage in Figure 1. The ADA also may have increased H to H1 since the atmosphere has changed to encourage the accommodation of employees with disabilities. We can assume that O<H since the construct of onsite work will be almost always more constrained than the home-based option.

The Americans with Disabilities Act seemed to give the onsite workplace some of the benefits traditionally saved for those who worked at home while strengthening the benefits of working from home. In Figure 1, those who are at point B are out of the labor force. Those who are on the line segment BC' are home-based workers and those who are on the line segment C'D' are onsite workers. In Figure 1, C'D' increased more than BC', so it would seem that the disabled would be drawn in greater numbers to onsite work rather than home-based work, although both could increase. This is consistent with the numbers found in Table 1.

Conclusion

People with disabilities in the United States had greater access to employment in 2000 than in 1990. Both the Americans with Disabilities Act and increases in technology seem to have had a large hand in the positive change in the employment landscape for those with disabilities. Since the ADA was enacted in part to bring these individuals into mainstream society, this is good news for the effectiveness of this legislation. According to the IPUMS data, in 2000, persons with disabilities were more likely to be working and less likely to be out of the labor force than in 1990. Those with disabilities entered the onsite workplace in droves, but also were accommodated by working from home.

The vast majority of those who entered the workplace went to onsite jobs, but home-based work provided an important place as well. Home-based work does seem to be a viable, yet underutilized, choice for those with disabilities. As the digital age continues to thrive, there is a greater place for home-based work opportunities. The onsite world of work may always be dominant, but the "reasonableness" of working from home increases with every technological advance. "Qualified individuals" with a disability must be "reasonably accommodated" under the auspices of the ADA. However, the *Vande Zande* holding, which is based on "excessive absenteeism" cases, virtually eliminates the possibility that home-based work could be a "reasonable accommodation." This presumption was faulty in 1995, but it is certainly flawed now. Lifting the *Vande Zande* presumption could increase the employment opportunities of those with disabilities, aligning with the original intent of the ADA.

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Endnotes

[1] I have used Kristen Ludgate's insightful law review article, "Telecommuting and the Americans with Disabilities Act: Is Working at Home a Reasonable Accommodation?" 81 Minn. L. Rev. 1309 (1997), as a jumping off point when outlining the legal history of the "reasonableness" of home-based work as an accommodation for disabled workers under the ADA in Part I of this section. I am indebted to Ms. Ludgate for the overarching structure, factual content and legal analysis of this part.

[2] See Mason v. Avaya Communications, Inc., 357 F.3d 1114 at 1118 (10th Cir. 2004); Kvorjak v. Maine, 259 F.3d 4 (1st Cir. 2001); Waggoner v. Olin Corp., 169 F.3d 481, 483 (7th Cir. 1999); Hypes v. First Commerce Corp., 134 F.3d 721 (5th Cir. 1998); Smith v. Ameritech, 129 F.3d 857 (6th Cir. 1997)

[3] Part II of Section II is based on "Home-Based Work and Women's Labor Force Decisions" by Linda Edwards and Elizabeth Field-Hendrey. The "before-ADA" part of Figure 1 and the theory come directly from this article.

"Vande Zande was argued in 1994 and decided in January 1995, when companies like CompuServe and AOL were just starting to provide Internet access to large numbers of in-home users and Amazon.com began selling books online. Less than a year before Vande Zande was published, Vice President Al Gore first coined the phrase 'information superhighway' in a speech outlining the administration's support of the fledgling Internet and its commitment to revolutionary growth in an information technology industry" (Valenza, 2004).

Disability, the Stigma of Asexuality and Sexual Health: A Sexual Rights Perspective

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Abstract: This article discusses the stigma of asexuality generally attributed to persons with disabilities. It examines how this stigma posses a barrier to attainment of sexual health. It argues that health programming must treat persons with disabilities as sexual subjects who have sexual rights in order to advance their sexual health.

Key Words: disability, stigma of asexuality, sexual rights

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HIV/AIDS is one of the challenges that persons with disabilities face today. There have been calls to include persons with disabilities as sexual subjects in HIV/AIDS programming. However, while such programs may indeed include persons with disabilities, the stigma that persons with disabilities are asexual can hinder efforts to adequately address their sexual health needs, including HIV/AIDS. The stigma operates to exclude persons with disabilities from being treated as sexual subjects having sexual rights.

The aim of this article is to explore the challenge posed by the stigma of asexuality in the context of sexual health, and to argue for the recognition of persons with disabilities as full sexual subjects. This is crucial because sexual health and HIV/AIDS prevention programs that do not also address the stigma of sexuality will fail to fully address the sexual health needs of persons with disabilities and may continue to marginalize them.

Constructing Disability

Before embarking on the discussion of sexual health as it relates to disability, the concept of disability itself shall be examined, as it is understood from various perspectives. Several models of understanding disabilities are discussed under the individual pathology and social pathology paradigms (National Human Rights Commission [India], 2005).

The Individual Pathology Paradigm

The charity model constructs persons with disabilities as unfortunate victims of nature gone awry and therefore deserving society's pity and charity. The location of the problem is in the individual, who by virtue of some physiological or psychological characteristic is labeled handicapped. Some say "handicap" literally derives from the image of a beggar with a "cap" in "hand." Policies on disabilities influenced by this mentality emphasize welfare and charity.

The medical model also focuses on individual pathology. The emergence of the medical model is associated with the rise of scientific thinking in the Enlightenment Period (Udwadia, 2000). The medical model is based on a positivist philosophy with its attendant assumptions about the nature of the social world and methods of investigating it. These assumptions consist of the belief that the world could be studied in the same way as the natural world, and that there is a unity of method between the study of the natural and social sciences (Rioux, 1994a).

The medical model conceives disability as impairment of an individual, and focuses on disability as an abnormality subsisting in the individual. A person with a disability is therefore measured against a certain standard of normalcy. He or she has a disability in so far as he or she has deviated from normalcy (Shakespeare, 1996).

The medical model with its scientific and positivist philosophical basis has a powerful influence on society. Smart & Smart (2006) say that the biomedical model carries the power and prestige of the medical profession that commands the respect of society. This is why disability seen through the medical perspective gained a strong foothold in many societies.

Locating disability in the person and conceiving disability as an objective condition subsisting in the person, also justified discriminatory treatment (Rioux, 1994b). What if a disability could not be "eliminated?" Inevitably, elimination of disability conflated with exclusion or elimination of persons having disabilities. This was done by institutionalization, segregation of schools, asylums and sheltered workshops.

The stigma and discrimination against persons with disabilities was also encouraged by the development of the science of eugenics. This was to have one of the harshest effects on persons with disabilities, because they were thought to be reservoirs of undesirable genes. Rioux (1994b) has noted as follows:

> "The enthusiasm of the eugenicist and psychometricians for finding a scale to measure innate difference was translated into scientific evidence of inferiority and superiority. In the hands of governments and lawmakers, the scale became a means to differentiate and justify unequal treatment, including the restriction of basic citizenship rights such as procreation, marriage, immigration, education, property ownership and ability to contract" (p. 72).

The stigma surrounding the sexuality of persons with disabilities was therefore legitimized by science. Denying their sexuality or imputing a perverted sexuality are two sides of the same coin; justifying the social and legal control of their access to sexual activity and expression, and most importantly, procreation. One way of perpetrating this was through involuntary sterilization. This mentality is reflected in the case of *Buck v. Bell* (1927) where Justice Oliver Wendell Holmes of the United States Supreme Court made the following statement in favor of the sterilization of a person with a mental disability:

> "It is better for all the world if instead of waiting to execute degenerate offspring for crime, or to let them starve for imbecility, society can prevent those who are manifestly unfit from continuing their kind … three generations of imbeciles are enough" (at 207).

The Social Pathology Paradigm

What has been called the functional or rehabilitation model is discussed here as an extension of the medical model, but at the same time as a precursor to the social model. In part as a result of further advances in medicine, and in part because of the need to reintegrate into a more or less normal life those citizens who had acquired disabilities because of two world wars (Kaplan, n.d.), there was the beginning of a shift from the individual pathology paradigm to the social pathology paradigm. The functional model perceives the person as needing assistance through services and supports aimed at making the individual as functional as possible (National Human Rights Commission [India], 2005).

This understanding of disability brought about the era of rehabilitation programs. This included services such as physiotherapy and occupational therapy, and skills training. Medical technology was harnessed in research to manufacture assistive devices, for the purposes of assisting the person with a disability to lead a normal or closer-to-normal life.

The advent of the rehabilitation era reflects a mind-shift from treating persons with disabilities as deserving charity or cure and justifying subtraction of rights, to regarding them as persons who were entitled to rights, and needed assistance to negotiate diverse environments.

The rehabilitation model paved the way for people with disabilities to question the authority of the medical model. The paradigm shift was complete when disability was conceptualized as the barriers society imposes on persons with disabilities. This has been referred to generally as the social constructionist model. According to Jones and Basser Marks (1998) "… the social constructionist approach to disability tries to uncover the subtle societal factors which interplay with personal experiences which and together create, reinforce and potentially perpetuate the subordination of persons with disabilities" (p. 3).

The social model therefore arose primarily as a critique of positive science, which posed as the dominant discourse. The social model of disability was a reaction to the conceptualization of disability by the biomedical sciences, which considered disability as an objective phenomenon in the individual (Diedrich, 2005).

The period following World War II saw the inception of the modern human rights movement. This spurred civil rights movements, including the disability movement, to frame their concerns in terms of human rights. Disability movements conceived advancement of their human rights concerns as an emancipatory and political project. They insisted on entitlement to full citizenship rights (Cole, 2007). They criticized the policies and laws that were based on the medical model, which perpetuated negative stereotypes, and justified the exclusion of persons with disabilities from the benefits of citizenship (Prince, 2004). Removing social barriers and achieving equality was central to the project:

> "Without a concept of social barriers to full participation in society, a movement from the welfare approach to a rights-based legal paradigm would not have been possible. People with disabilities could not be conceived as equals while there was an automatic assumption of inferiority and incompetence" (Jones & Basser Marks, 1998, p. 6).

The social model is not without criticisms (Terzi, 2004). It is not within the scope of this essay to examine these. Suffice to say that the medical model and the social model have contributed to the conceptualization of disability and continue to be influential in social policy and law (Ngwena, 2006). Therefore, an integrated approach that combines both models greatly enhances the potential to empower persons with disabilities. Most importantly, it also allows disability to be a subject of human rights. Persons with disabilities are therefore subjects of human rights including sexual rights. Disability does not subtract any human rights from any human being.

Sexual Rights and Related Concepts

The thinking about sexuality in the context of rights, and eventually evolving into the framework of sexual rights, has gained visibility on international political agendas only recently. The subject of sexual rights therefore is still evolving.

The concept of sexual rights is explored here, and the related concepts of sexuality and sexual health, which are pertinent to the discussion of sexual rights as it relates to persons with disabilities. The World Health Organization (WHO) has through consultation with experts come up with definitions of these concepts, and they shall be adopted in this work. The advantage of adopting these definitions, though not official WHO positions, is that they come from an authoritative world-body and enjoy wide political legitimacy. However, this is not to gloss over the fact that these concepts may not enjoy unanimous acceptance.

Sexuality and Sexual Health

The difficulty of coming up with one universally acceptable concept of sexual rights arises from the fact that sexuality itself, which is the subject of sexual rights, is a term imbued with many meanings (Weeks, 1986). To begin deconstructing the term, the different philosophical underpinnings of its conceptualization need unraveling. Two main perspectives have shaped the understanding of sexuality: essentialism and social constructionism.

Essentialism implies the belief that certain phenomena are natural, inevitable, and biologically determined (DeLameter & Hyde, 1998). From this perspective, sex and sexuality are intricately linked to reproduction, and women's sexuality to motherhood. One consequence of such conceptualization is the institutionalization of heterosexuality, where family and marriage are the privileged sites of sexual intercourse and child rearing (Carabine, 2004).

From the social constructionist perspective, sexuality is not a biological given but is socially and culturally constructed (DeLameter & Hyde, 1998). Sexuality therefore is a social construct whose meaning is derived from language or discourse; a way of thinking and talking about behaviors that are considered sexual or not sexual (DeLameter & Hyde, 1998). Carabine (2004) says that the social constructionist perspective places emphasis on the social meanings that an individual attaches to specific sexual acts, behaviors, feelings, desires and relationships.

Another feature of sexuality is that it is experienced at the individual and personal levels as well as at the social level. Carabine (2004) says that:

> "At a personal level, sex and sexuality may invoke different sets of ideas and feelings in us to do with intimacy, privacy, pleasure, excitement, desire, embarrassment, attraction, age, fear, pain, abuse, control, freedom, fulfillment, danger, constraint, disease, well-being, our bodies, love and emotion" (p. 2).

At the sociocultural level, sexuality is constructed to serve a variety of needs: sex is a means of procreation, an intimate bonding ritual, even a form of social control (Rye & Meaney, 2007). It is this characteristic of being private and at the same time public, arising as a biological given and at the same time socially constructed, that sexuality is a highly contested and contradictory terrain. Its malleability and capacity to evoke varied interpretations invokes fierce political and public debate (Carabine, 2004).

Ultimately, a useful definition would try to capture these aspects of sexuality. The working definition by WHO (2004) International Technical Consultation on Sexual Health affirms the complexity of the term:

> "Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. . . . Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors."

From this discussion and definition, it is appreciated that sexuality is a central aspect of being human and is experienced in diverse ways. The experience of sexuality is also dependent upon the interplay of various biological and social factors.

The definition of sexual health logically flows from the definition of sexuality. The definition of sexual health by WHO (2004) is one of the most influential definitions today, but by no means the only one:

> "Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

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

Certain aspects of this definition deserve to be highlighted. First, sexual health is not merely the absence of disease, dysfunction or infirmity. The other aspect is that sexual health may not be attained without the respect, protection and fulfillment of sexual rights.

Sexual Rights

The agenda for sexual rights emerged at two world conferences: the International Conference on Population and Development (ICPD) of 1994, and the Fourth World Conference on Women (FWCW) of 1995. The Beijing Platform for Action (1995) defined sexual rights in the following terms:

> "The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence" (para. 96).

Though a great achievement for the recognition of sexual rights, this definition was not a complete victory, and the quest for legitimacy continues. Petchesky and others, for instance, criticize this definition for "bracketing" sexual rights and conflating them with reproductive rights (Miller, 2000; Petchesky, 2006).

WHO (2004) defines sexual rights as the right of all persons, free of coercion, discrimination and violence to: the highest attainable standard of sexual health, including access to sexual and reproductive health care services; seek, receive and impart information related to sexuality; sexuality education; respect for bodily integrity; choose their partner; decide to be sexually active or not; consensual sexual relations; consensual marriage; decide whether or not, and when, to have children; and pursue a satisfying, safe and pleasurable sexual life.

Though it has been stated that sexual rights are not new rights, but rather the existing rights applied to sexuality (Klugman, 2000), sexual rights pose a problem where there is no consensus regarding certain aspects of sexuality. One example where controversy is still rife is sexual orientation. Horn (2006), for instance, reminds us that Africa in general is hostile to sexual expression that is not heterosexual. It is thus not surprising that feminists, gays and lesbians, and other marginalized groups have been in the forefront in the struggle for recognition of sexual rights (Eager, 2004). Their political agenda, being perceived as subversive to mainstream thinking about sexuality, has usually met fierce resistance (Long, n.d.). It is therefore not surprising that confronting the stigma of asexuality may raise similar challenges.

Disability and Sexuality: The Dis-ease

Persons with disabilities face the stigma of asexuality. An exploration of this stigma and how it affects persons with disabilities enables an appreciation of the challenges persons with disabilities face. This discussion also reveals the uneasiness of human rights instruments and disability movements to affirm sexuality of persons with disabilities.

Stigma

The stereotype that ascribes asexuality to persons with disabilities is a general phenomenon in society. Following from the definition of sexuality, asexuality could mean lack or deficiency to express or experience any one or more of the elements constituting sexuality.

The stigma of asexuality has adverse effects on the sexual well being of persons with disabilities. Shakespeare, Gillespie-Sells, & Davies (1996) in their groundbreaking book have given an insightful account of the impact of this denial of sexuality on persons with disabilities. Persons with disabilities face various hindrances to their sexuality. This includes lack of sexual self-esteem, failure to enjoy pleasurable sex, and failure to get sexual partners (Tepper, 2000; Yoshida, 1999). Their access to sexual expression may be limited or excluded (Shuttleworth & Mona, 2002; Wade, 2002). They generally experience higher levels of sexual abuse (Naidu, Haffejee, Vetten, & Hargreaves, 2005). They are thought of as incapable of consenting to sexual relationships so that they are on one hand protected by the law from sexual abuse, but on the other denied sexual relationships (Evans & Rodgers, 2000). The health care system or other institutions may fail to address their sexual health needs (Kvam & Braathen, 2006).

Weeks reminds us that sexuality is socially regulated by traditional mores, customs, and other non-state systems (1998). However, legal and social policies play a role in shaping sexuality. Generally, it is only when sexuality is perceived as a problem that policy and law make appearance, as in the case of homosexuality, the sexuality of persons with mental disabilities, and under-age sex. Regulation of sexuality appears in the form of protecting vulnerable individuals from undesirable and unwanted sexual experiences, through criminal legislation, sex education policies, and disability policies (Carabine, 2004).

Where policy and law maintain silence on sexuality, it may not necessarily mean that they are not regulating sexuality. Rather, argues Shildrick (2007), the silence may imply the assumption of dominant constructions of sexuality. Silence may actually actively construct persons with disabilities as asexual. The dominant construct posits as the norm the heterosexual relation between two putatively equal adults, whose sexual practice is primarily genital based, procreation oriented, and privately conducted (Shildrick, 2004).

Shildrick therefore argues that social and legal policies always have some form of regulation on sexuality. Generally, persons who exhibit sexuality that conforms to heteronormativity have the benefit of the positive aspects of this social regulation.

Due to disability, persons may have a body morphology or mental ability that makes them unable to conform to heteronormativity. For instance, they may be unable to experience genital effect or verbally communicate their needs and desires. They may not be able to conceive. Their sexual organs may not be fully functional, or they may need physical support to be able to engage in sexual activity (Shildrick, 2004). When the sexual practices of persons fall outside the normative range then their sexuality is not legitimized or recognized (Shuttleworth, 2007a).

The stigma of asexuality will depend on the kind and extent of disability. It is not merely that the disabled body may not be aesthetically appealing according to social meanings of attractiveness, though that may be part of the reason persons with disabilities experience stigma. However, a major determining factor of the stigma is the extent to which the physical or mental disability has the potential to, or actually challenges the dominant norms governing sexuality. When disability subverts the heteronormative values and hegemonic masculine expectations (Shuttleworth, 2007a) of society, it is bound to be stigmatized. Wilkerson (2002) says:

"If heterosexual vaginal intercourse is taken as the norm, the sexual practices of many will not seem to count as sex at all. Knowledge of diffuse male sexualities may be culturally suppressed, or even incomprehensible, because they are perceived as incompatible with masculinity, while for women such pleasures are perceived as outside the domain of legitimate heterosexual experiences. The repercussion for those with physical disabilities, like many others, may be silence and unintelligibility, their sexualities rendered incoherent, unrecognisable to others or perhaps even to themselves, a clear instance of cultural attitudes profoundly diminishing sexual agency and the sense of self and personal efficacy which are part of it" (p. 48).

Stigma is stronger when disability is more severe. It should also be realized that oppression based on this stigma intersects with other oppressions such as gender, age, socioeconomic status and race (Shuttleworth, 2007a). However, the current essay is pitched at a general level and will therefore not delve into these facets of oppression.

Shildrick (2004) calls attention to the fact that social and legal policies, and sexuality, are mutually constitutive in that they shape one another. In other words, change in how policy constructs sexuality may redefine how persons understand sexuality. Conversely, how persons understand their sexuality may influence policy.

That social policy is constitutive of sexuality is at once a hurdle but also opportunity for negotiation. This is because if persons with disabilities can redefine their sexuality to suit their bodily and intellectual experiences, that reconstruction feeds back into how the wider society understands disability and sexuality, and may challenge society to reconstruct sexual norms (Reynolds, 2007).

By maintaining the dominant discourse of sexuality and suppressing other minority views, social and legal policies perpetuate the stigma of asexuality and exclude persons with disabilities from being regarded as sexual subjects. Maintaining silence about sexuality in sexual health programs of persons with disabilities lends support to the stigma of sexuality.

Disability and Sexuality in Human Rights Instruments

The dis-ease with sexuality as it relates to disability is reflected in human rights instruments. The recently adopted Convention on Rights of Persons with Disabilities (Convention) shies away from portraying persons with disabilities as sexual subjects. The Convention does not explicitly mention sexuality and sexual relationships. The term "sexual" is mentioned in article 25(a) of the Convention, in the context of health and only in conflation with reproductive health. Otherwise it mentions the right of persons with disabilities to marry and have a family, which prima facie is a narrower context than sexual relationships.

However, prior to this Convention, the Committee on Social, Economic and Cultural Rights in its General Comment No. 5 (paras. 30 & 31), had stated that laws and social policies and practices should not impede the realization of the rights of persons with disabilities to marry and form a family. Quinn and Degener (2002) noted that:

> "Comment No. 5 reiterates Rule 9(2) of the Standard Rules, stating that 'persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.' It then stresses that 'the needs and desires in question should be recognised and addressed in both the recreational and the procreational contexts'" (section 5.3.4).

It is submitted that the Convention could have addressed sexual relationships as the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (StRE) do. It may be argued that the recognition of the StRE in the preamble incorporates them in the Convention. Nevertheless, the Convention being an important standard-setting document should have expressed this more explicitly and thus affirm persons with disabilities as sexual subjects and bearers of sexual rights.

Human rights instruments have provisions that explicitly recognize the right to sexual health. These include article 25 of the Convention, and article 14 of the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa. Though other provisions do not mention sexual health explicitly, it is submitted that these incorporate sexual health as well, such as article 25 of the Universal Declaration of Human Rights, article 12 of the International Covenant on Economic, Social and Cultural Rights, article 16 of the African Charter on Human and People's Rights, and article 12 of the Convention on the Elimination of All Forms of Discrimination against Women. Arguably, these provisions bear the closest relationship to affirming sexual well being through the concept of sexual health as defined by WHO. These provisions therefore have an important bearing on sexuality, and guarantee persons with disabilities the right to sexual relationships, activity and pleasure, free of coercion and disease. They refer to other correlative rights articulated in various other human rights provisions. These include the right to access information, communication and information relating to HIV/AIDS and other health issues.

However, the conflation of sexuality and reproduction again suggests heteronormative underpinnings. This may perpetuate stigma against persons with disabilities.

Another caution is that reference to health may also tend to medicalize sexuality of persons with disabilities, for instance the case of male impotence. Much as persons can derive benefit from treatment of impotence, Shuttleworth (n.d.) and others (Tiefer, 1994; Wentzell, 2006) have warned against this being a guise of serving heteronormativity, where the biomedical-driven project is to fix the person's body to fit the heteronormative and masculine morphology.

To reiterate, human rights instruments have tended to maintain silence on sexuality of persons with disabilities. This silence favors constructing persons with disabilities as asexual rather than affirming their sexuality.

Sexuality and Disability Movements

Disability movements around the globe, most especially in the developed countries in Europe and North America, have taken up the struggle for a positive affirmation of sexuality. Claims have been made that governments should fund sexual encounters for them as captured in a news article by *Ananova* ("Danes Provide Prostitutes," n.d). Some organizations have actually facilitated sexual encounters for persons with disabilities (Ilkkaracan & Jolly, 2007).

In contrast to disability movements from the Europe and North America the general trend in Africa is to dwell on the prevention of violence and HIV/AIDS, and less on tackling the stigma of asexuality.

The then Organisation of African Unity (now African Union) in 1999 proclaimed the African Decade of Persons with Disabilities (1999-2009) and adopted the Continental Plan of Action for the African Decade of Persons with Disabilities (Continental Plan of Action). This Continental Plan of Action is an undertaking that aims at bringing the concerns of persons with disabilities on the broader social agenda. In the area of sexual health, an activity that is enjoying prominence and is spearheaded by the African Secretariat of the African Decade for Disabled Persons is the campaign against HIV/AIDS. A booklet made for the campaign states, "The stigma experienced by persons with disabilities means that they are *less likely to marry and more likely to have several sexual partners* in a series of unstable relationships" (Secretariat of the African Decade of Persons with Disabilities, n.d., p.2) (italics supplied).

The Continental Plan of Action mentions the stigma of asexuality but only in passing. The main subject is HIV/AIDS. The same is also observed in the agendas of regional organizations such as the Southern Africa Federation of the Disabled (SAFOD), which is the umbrella organization for disabled people's organizations (DPOs) in Southern Africa. At its website, where SAFOD outlines its programs, sexuality is mentioned only under prevention of HIV/AIDS. Sexuality is not a subject that is given prominence in its own right.

In Malawi, the disability movement is spearheaded by the Federation of Disability Organizations in Malawi (FEDOMA), the umbrella organization coordinating the activities of DPOs. While it is doing a great deal to advance the rights of persons with disabilities in areas such as education and employment, it is only just beginning to look at sexuality. As the general trend in Southern Africa, it is predominantly under the theme of HIV/AIDS or reproduction (FEDOMA, n.d.).

However, several recent research projects carried out with the collaboration of FEDOMA, while not directly on sexuality of persons with disabilities, do open up spaces for discussing sexuality.

The first research project concerns the living conditions of persons with activity limitations in Malawi (Loeb & Eide, 2004). This study did not investigate the sexuality of persons with disabilities. However, the following statement by Loeb and Eide is interesting:

> "Somewhat surprising, it was found that need for emotional support surpassed economic support when asking for what type of assistance that was needed in daily life. … This is important to bear in mind when developing services for people with disabilities, as emotional needs will more readily be neglected when there is so much to do in terms of practical help" (p. 150).

This is an important observation. Sexual health encompasses psychological and social structures of support. This finding could very well reflect the need to provide emotional support in the area of sexual health amongst other concerns.

In 2004, a study was carried out designed to explore and understand the sexual and reproductive health needs and experiences of people with disabilities, their perceptions about HIV/AIDS and how best information on HIV/AIDS can be communicated to people with various forms of disabilities (Munthali, Mvula, & Ali, 2004). One observation about this survey is that it assumed heteronormative values. The participants were asked questions about marriage and sexual intercourse with the understanding that these are the norms. This has the effect of excluding information regarding other ways of experiencing sexuality. Despite this drawback, this survey did elicit a number of issues pertaining to sexuality.

The research revealed issues including failure to establish relationships because of limitations of mobility, speech problems, negotiation of relationships and failing to establish partnerships. Munthali et al. captured some of the underlying reasons: "… It is extremely difficult for persons with disabilities to establish intimate relations with those who are not disabled because people with disabilities are generally viewed as useless and unproductive" (p. 67).

The research found that 55.9% of the research subjects had difficulties forming sexual relationships for reasons such as fear of HIV/AIDS, fear of pregnancy, and feeling shy. The report concluded that most of the responses were related to the individuals' negative perceptions of themselves.

Evidence from other research elsewhere indicates that young people with disabilities experience rejection from adults and peers, and exclusion from information sharing regarding sexuality (Motangolingoane-Khau, 2006). Other research reveals how the stigma of asexuality damages sexual self-esteem of young disabled persons (Potgieter & Khan, 2005).

In general, there is shying away from confronting the stigma of asexuality in Africa. There may be several reasons for this. One reason is that sexuality is taboo and to bring up the topic for discussion in public, even for persons who are non-disabled, causes discomfort (Malawi Human Rights Commission, 2006). On the other hand, might it be that what Shakespeare (2000) says holds true for Africa as well?

> "I think that sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level—both acceptance of oneself, and acceptance by significant others—and forces people to confront things which are very threatening, given the abusive and isolated lives of many disabled people. As Anne Finger suggests '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'" (p. 160).

Another reason may simply be that sexuality is not considered as important in the light of other concerns that are thought to be more pressing such as poverty, education and employment. If this is the contention, perhaps the following reflection by Crow cited in Shakespeare et al. (1996) may begin to challenge this thinking:

> "I've always assumed that the most urgent disability civil rights campaigns are the ones we're currently fighting for – employment, education, housing, transport etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're looking for… It's not that one area can ever be achieved alone – they're all interwoven, but you can't get closer to the essence of self or more 'people-living-alongside-people' than sexuality can you?" (p.206).

In order to advance sexual health for persons with disabilities, such as prevention of sexually transmitted infections, it is necessary to find ways and means of confronting the stigma of asexuality, and to affirm the sexuality of persons with disabilities.

Integrated Sexual Health Care

Sexual Access

When considering sexual health care for persons whose disabilities attract the stigma of asexuality, Shuttleworth argues that we must focus on what is central to the sexual needs of persons with disabilities. He introduces the concept of sexual access as a tool for focusing the discussion on sexuality (and sexual rights) of persons with disabilities.

The concept is premised on the recognition that first and foremost, the stigma of asexuality places restrictions on persons with disabilities in their attempt to negotiate sexual relationships with others (Shuttleworth, 2007a). However, sexual access is not just about physical intimacy. Shuttleworth and Mona (2002) say that, "By sexual access we do not mean access to physical intimacy per se. Rather, we mean access to the psychological, social and cultural contexts and supports that acknowledge, nurture and promote sexuality in general or disabled people's sexuality specifically" (p. 3).

The inability of society to nurture the sexuality of persons with disabilities hinders sexual access and results in poor sexual self-esteem (Shakespeare, 2000).

Sexual access can be broken down into two aspects. The first aspect of sexual access is the psychological, social and cultural supports that acknowledge and nurture sexuality and the individual's need for sexual expression and intimate relationships. The second aspect of sexual access encompasses the opportunity for an encounter with the other. The person should have the opportunity to access the social and interpersonal space in which mutual desire is evoked and sexual negotiations become possible (Shakespeare, 2003).

The notion of supporting sexual access of persons with disabilities may bring up controversial issues with potential to evoke highly emotionally charged discussions within, without and across the disabled and non-disabled communities. These include facilitated sex (Davies, 2000; Shuttleworth, 2007b; Tepper, 2006) and sexual surrogacy (Shapiro, 2002). Despite the controversies and dis-ease these ideas may churn, Shildrick (2004) comments that:

> "Whether you are able-bodied or disabled, you may find the idea of facilitated sex shocking, commendable or immoral… One thing is sure: however we view the dilemmas, the idea of facilitated sex does force us all to acknowledge the sexuality of disabled people" (p. 153).

The sexuality of persons with disabilities may therefore not be ignored because certain norms are challenged by the concept of sexual access. At stake is the humanity of persons with disabilities. They are sexual subjects too. They have sexual rights.

Sexual Health Programming

Sexual access should be the guiding concept in sexual health programs for persons with disabilities. Sexual access keeps us aware that persons with disabilities wish to pursue their fullest sexual health, through sexual expression and experience, and not merely to avoid contracting sexually transmitted diseases and infections. Sexual health programs should respect the full sexual and reproductive rights of persons with disabilities. This could include strong presence of counseling components to help persons with disabilities negotiate the barriers of sexual access of which the stigma of asexuality is the greatest.

Health programming should also accept the full implications of sexual health that includes diversity of experiences and expressions of sexuality. The health sector should train health practitioners who are sensitive to the needs of persons with disabilities especially in the area of sexuality. It may not be easy to achieve full sexual access for persons with disabilities, but the health system can certainly reduce the stress, which persons with disabilities may actually meet pertaining to their sexual health.

Perhaps the greatest challenge is to get persons with disabilities to start appreciating their own sexuality needs, and to be able to express them in an environment where these concerns will be appreciated and their sexuality affirmed. The health system should be the leader in providing such an environment.

Conclusion

Though HIV/AIDS is indeed one of the greatest public health challenges, when it comes to persons with disabilities, dealing with the stigma of asexuality may be as important as dealing with HIV/AIDS. It must always be kept in mind that in the end, HIV/AIDS is one aspect of sexual health, and attaining sexual health is not just avoidance of HIV/AIDS or dealing with this infection. Sexual health will be attained by paying attention to all aspects of sexual health including dealing with the stigma of asexuality. Sexual health will be attained by respecting sexual rights.

Persons with disabilities seek a full experience and expression of sexuality and should not be hindered by prejudiced views towards their sexual capacities. However, confronting HIV/AIDS remains one of the greatest challenges under sexual health and for persons with disabilities. This article's emphasis on dealing with the stigma of asexuality does not in the least diminish this fact. It rather seeks to enhance the quality of HIV/AIDS programming for persons with disabilities.

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Policy Legitimacy: A Model for Disability Policy Analysis and Change

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Abstract: In this paper we present and apply Legitimacy Policy, a framework for policy analysis that applies a legitimacy lens to the examination, understanding, and illumination of directions for purposive policy change. Interrogating historical and current disability policy: (a) reveals the context-based value-foundations and continued dominance of medical explanations of disability inherent in disability-specific policy and (b) maps a direction for policy change that can advance human rights for disabled citizens.

Key Words: policy, legitimacy, values

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Introduction

In this paper we present, discuss, and illustrate a contemporary disability policy analysis framework: Explanatory Legitimacy. Although applied to several seminal policies in the U.S. for illustration, the model is useful and potent at all levels of policy formulation and promulgation. The conceptual framework synthesizes principles from legitimacy theory and pragmatism, creating a scaffold in which to look at the evolution of ideas and principles within axiological and purposive contexts. We conclude with the application of the analytic model to disability policy exemplars.

> Before we begin the discussion we pose three definitions.
>
> Policy – Policy definitions range from informal rules that govern conduct and access to resources at multiple system levels to formal legislation advanced by government bodies. In this paper, we define policy as the set of explicit statements that guide legitimate status and responses to membership status in the form of resource access, allocation, and other action responses to legitimate category members.
>
> Disability - As we discuss in detail below, we define disability as a contextually embedded, dynamic grand category of human diversity.
>
> Disability policy – Disability policy is complex and thus we have parsed it into three subdivisions; disability-exclusive policy, disability-embedded policy, and disability-implicit policy. Disability-exclusive policy is the set of explicit statements that legitimate membership criteria in the disability category and guide responses to legitimate category members. Disability-embedded policy has a similar function to exclusive policy, but disability is one of two or more groups addressed in the policy. Disability-implicit policy does not name disability but tacitly defines and responds to it through its prevention, elimination, or manipulation.

Explanatory Legitimacy Theory

Explanatory Legitimacy Theory is embedded within and builds on the genre of legitimacy theories, which have a long, interdisciplinary history. According to Zeldich (2001), legitimacy theories can be traced as far back as the writings of Thucydides in 423 B.C., in which questions were posed and answered about the moral correctness of power and its muscled acquisition. The birth of legitimacy theory in political theory renders it potent for policy analysis, as it has been applied to numerous domains, including but not limtied to social norms and rules, distributive justice, and power. And while there are differences in the application of legitimacy theories to diverse substantive questions, what all have in common is their search for credibility and normative acceptance. That is to say, legitimacy theory examines the basis on which a phenomenon is seen as genuine or authentic.

Legitimacy theories have posited a range of factors that determine the authenticity or acceptability of laws, rules, or determinations. These elements can be explicit, such as public consensus about genuiness, or tacit as in efforts to obscure power brokering (Zeldich, 2001). Among legitimacy theorists, Weber is perhaps best recognized for his assertion that social order inherent in values, norms, and beliefs cannot be maintained without acceptance of this order as valid (Lembcke, 2007). Applied to policy, legitimacy theory has the potential to denude the normative beliefs that underpin hierarchies, power relationships, and categorization and to expose the values that imbue category status and acceptable responses.

In the tradition of legitimacy theories, Explanatory Legitimacy Theory seeks to analyze, detangle, and clarify categorization and response by focusing on the the source of authentification and valuation of explanations for category membership. Rather than focusing exclusively on political power as its object and subject, Explanatory Legitimacy Theory is concerned with the credibility, value, and purposive acceptance of causal theories which parse and assign humans into groups and then fashion responses to group members. Thus Explanatory Legitiamcy calls upon pragmistism to locate category placement and response as well as category creation within a purposvie perimeter.

Given the debates about the nature of disability, Explanatory Legitimacy provokes thought and analysis of diverse policies and has the potential to validate the use of each within different purposive contexts. Moreover, capitalizing on the clarity of seminal legitimacy thinkers such as Habermas and Parsons, the Explanatory Legimacy framework clarifies theory types so that each can be compared to those similar in structure and subject. Explanatory Legitimacy Theory builds on historical and current diversity analyses and debates as well. Different from locating disability in a singular domain of the body or the environment, Explanatory Legitimacy analyzes the construct of disability as a contextually embedded, purposive, dynamic grand category of human diversity. Thus, who belongs and what policy responses are afforded to category members are based on differential, changing, and sometimes conflicting judgments about the value of explanations for diverse atypical human phenomena. Explanatory Legitimacy considers the influence of multiple factors on value judgments as the key to understanding categorization, the legitimacy of individuals and groups who fit within a category, and the policy responses that are deemed legitimate for members.

Explanatory Legitimacy Theory makes the distinctions among descriptive, explanatory, and the axiological or the legitimacy dimensions of the categorization of human diversity, and identifies the relationships among these elements. Thus, similar to legitimacy-based analyses of other areas of human diversity, disability that is defined and analyzed through the lens of Explanatory Legitimacy is comprised of the three interactive elements: description, explanation, and legitimacy. This tripartite analytic framework provides a potent platform through which to examine policy responses to members of categorical groups (DePoy & Gilson, 2008). Let us look at each element now.

Description

Description encompasses the full range of human activity (what people do and do not do and how they do what they do) appearance, and experience. Of particular importance to an understanding of disability definitions and policy responses is the statistical concept of the "norm." Because the understanding and naming of what is normal and, in contrast, not normal are value-based, use of terms such as normal and abnormal do not provide the conceptual clarity sufficient for distinguishing description from axiology. Thus, in applying Explanatory Legitimacy to disability policy, we use the terms typical and atypical to depict frequently and infrequently occurring human description respectively. Disability is located in the realm of the atypical.

Explanation

The second element of Explanatory Legitimacy is explanation. Applied to disability, explanation is the set of reasons for the atypical. What is important to highlight with regard to the link between description and explanation is that explanation is always an inference. Because of the interpretative nature of explanation, this definitional element lends itself to debate, differential value judgment and diverse policy responses. As we discuss further in more detail, the current explanatory debate between two explanatory genres (interior and exterior causes of disability) is a heated one and has great relevance for policy. Interior causes attribute atypical phenomena to a medical-diagnostic condition of long term or permanent duration (Smart, 2001), while the exterior lens identifies an unwelcoming and even discriminatory environment as causal of disability, in which the atypical is met with barriers and exclusion.

Legitimacy

The third and most important definitional element of Explanatory Legitimacy is legitimacy, which we suggest is comprised of two sub-elements: judgment and response. Judgment refers to value assessments of competing groups on whether or not what one does throughout life (and thus what one does not do), how one looks, and the degree to which one's experiences fit within what is typical, have valid and acceptable explanations consistent with both explicit and implicit value sets. Category membership, in this case, is a purposive, value-encased determination about the extent to which the posited explanation for the atypical renders individuals and groups eligible for disability category membership.

Responses are the actions (both negative and positive) that are deemed appropriate by those rendering the value judgments about membership and responses to category members. Disability policy lies in the response element of Explanatory Legitimacy, at multiple points in time, beginning with the decision to consider the need for a category specific policy, proceeding to the promulgation of the actual policy, continuing with who is legitimately eligible for consideration under the policy, and finally to the response to legitimate category members guided by the content and nature of the policy. Thus teasing apart description, explanation, and values provides the opportunity for understanding and analyzing policy formulation and enactment from a complex, context-embedded perspective.

Explanatory Legitimacy Analysis of Policy

Typically, disability policy has been categorized into two areas: policies that guide the provisions of specialized services and resources, such as Social Security Disability Insurance (SSDI) in the U.S. that was established by the Social Security Amendments of 1956 (Berkowitz, 1989) for legitimately disabled populations, and, more recently, policies that protect and advance the civil rights of legitimately disabled populations such as the Americans with Disabilities Act (ADA) (Scotch, 2001). However, through the lens of Explanatory Legitimacy, and in the context of the 21st century, we suggest a different taxonomy that is depicted in Table 1.

Three analytic dimensions are presented in Table 1.

Dimension 1. The horizontal axis consists of four divisions of policy on the basis of both content and explicitly intended outcome. As illustrated by our exemplars, these categories are not mutually exclusive. Moreover, the policies that we chose as exemplars are not exhaustive by any means but they offer a range of diverse approaches to disability policy in the U.S. that can be applied to policy in other countries as well.

Legitimacy as worthy of life refers to policies that are concerned with conferring and removing life. These are underpinned by ascribing worth to the nature and circumstances of life as well as one's legitimacy for protection against fatal harm. Legitimacy of citizen participation, the second division, contains policies that situate individuals and groups as bona fide, partial, or excluded members of their local, state, national and global communities. The third division, legitimacy of citizen responsibility, addresses the extent to which citizens are held accountable for their behavior and its consequences. Legitimacy for material and rights benefits contains policy that is concerned with the distribution of resources and access to freedoms and rights. This division is divided further into three sub-categories: safety-net benefits or welfare support for those who are not gainfully employed, access to opportunity for remunerative employment, and conferral of more general rights to participate in civic, economic, and community life.

Dimension 2. The vertical axis of Table 1 contains two divisions, interior- and exterior-focused policy, each responding to its particular explanatory approach to disability. From a simple and linear standpoint, we would expect that the policies that fall under the division of interior-focused, on the basis of explaining legitimate disability as an embodied condition, would guide treatment or responses to bona

Table 1

New taxonomy for disability policy using Explanatory Legitimacy Theory

	Legitimacy as worthy of life	**Legitimacy of citizen participation**	**Legitimacy of citizen responsibility**	**Legitimacy for material and rights benefits**		
				Safety net benefits for non-workers	**Benefits to access opportunity for remunerative employment**	**Generalized rights to participation**
Interior Explanations	Prenatal testing Abortion rights (EM) Genetic manipulation EM)	Rehabilitation Act of 1954 (EX) Rehabilitation Act of 1973(EX) ADA (EX)	Death penalty and MR (EX)	SSDI (EX) SSDI (EX) Medicare (EM)	Rehabilitation Act of 1954 (EX) Rehabilitation Act of 1973 IDEA (EX)	ADA Golden Access Passport (free entrance into National parks) (EX) IDEA (EX)
Exterior Explanations	Death penalty (I) Freedom from harm (EM) Protection from Hate crimes (EM)	Rehabilitation Act of 1954 (EX) Rehabilitation Act of 1973 (EX) ADA (EX) Immigration Laws (EM, I)	Environmental laws (I) OSHA legislation (I) Motor Vehicle laws (I) Food safety (I)	SSI (EM) Medicaid (EM)	Ticket to Work and Work Incentives Improvement Act of 1999 (EX) GI Bill (EM)	ADA (EX) Voting Rights (I)

*EX-Disability Exclusive, EM-Disability Embedded, I-Disability Implicit fide category members. Similarly, exterior policies accept external disability explanations as legitimate and would be expected to address the barriers that exclude disabled groups from participation and rights. However, the divisions are not as simple as they might be.

Dimension 3. Since our last publication about policy, we have expanded our thinking. This dimension, detailed above, reflects that disability policy is not always explicit or exclusive to disability determination and response. We therefore have categorized disability policies as exclusive, embedded, and implicit as described above.

To understand Table 1, we now look at the policy exemplars through the lens of Explanatory Legitimacy. We suggest that, different from analyzing disability policy through its explicit content, intended outcomes, and language usage, policy is much more complex than its verbiage. Using the framework of Explanatory Legitimacy, disability policy is a value-based purposive response to explanations of atypical human characteristics and thus can be understood and changed by laying bare its value and pragmatic stance. Moreover, there are commonalities that unite disability-exclusive policy and distinguish it from disability-embedded and implicit policy that we present in Table 2.

Heuristics of disability policy using Explanatory Legitimacy Theory

As we see by the heuristics, Explanatory Legitimacy suggests that because values and context mediate logic, disability policy is not linear and cannot be understood through rational policy-analysis approaches. This observation is consistent with non-rational models of policy analysis (Stone, 2001). Second, although some exclusive policies as shown in Table 1 are targeted at changing the environment, legitimacy for coverage under these policies is restricted to interior explanations of disability. This disjuncture (DePoy & Gilson, 2008) becomes problematic in trying to understand the link between the articulated problem that the policy is designed to remediate and the causal assumption. Third, atypical embodied characteristics that are observable and assumed to be caused by conditions beyond the control of the individual are often more legitimate for disability category membership than those which are not directly ascertainable and/or considered to be caused by factors over which individuals have control. Fourth, disability theory and policies are frequently based on assumptions about the commonalities of a group, which may or may not be accurate. And fifth, in a global economic context, disability-exclusive, embedded and implicit policies, similar to all federal policy, directly or indirectly address resources. Finally, we discuss the last heuristic, #6, toward the conclusion of the paper.

Policies That Support Prenatal Testing

Policies that support prenatal testing for interior genetic or corporeal compositions create provisions for screening in the service of termination or correction of fetal viability under certain circumstances. We use the term fetal viability to clarify that this discussion is not about the ethics of termination of life, genetic manipulation, or women's rights to choose. Rather, we have included and classified these policies as disability-embedded because they stipulate conditions, such as Down Syndrome, a genetic condition that is considered to be disabling, under which termination of pregnancy is legalized and supported by policy. Other conditions, such as spina bifida, can be corrected by genetic or medical intervention. In either case, opponents of this policy genre argue that it devalues genetic diversity and eliminates it through killing or medical correction. We have located these policies as interior explanations and under the category of legitimacy as worthy of life, on the basis of assumptions about lack of desirability and thus acceptability of preventing a life with specific atypical interior genetic composition.

Heuristics of disability policy using Explanatory Legitimacy Theory

1. Values and context mediate logic and thus exclusive, embedded and implicit disability policy is not logical
2. All disability-exclusive policies, even if guiding exterior action, emerge from an interior causal explanation of disability.
3. Unlike disability-exclusive policy, disability-embedded and implicit policy, because they expand their scope beyond medicalized interior criteria, may posit disability as exterior and without inherent interior explanations.
4. Interior policies are organized along a value hierarchy of medical interior explanations and not all explanations are acceptable.
5. Disability-exclusive policy is based on nomothetic assumptions about a group that does not necessarily share commonalities.
6. Disability-exclusive and some disability-embedded policy have distributive foundations.
7. Disability-exclusive policy, while temporarily needed, may have long term consequences of segregation and inequality.

As noted by Scully (2008), prenatal testing and its potential consequences not only foreground devaluation of certain genetic compositions but reify them as pathology and disability. Conversely, in concert with heuristic #6, utilitarian arguments are often made in favor of these policies, given that it is assumed that genetic interior explanations for disability will be costly in resources and time.

Social Security Disability Insurance (SSDI), Medicaid, Medicare, Ticket to Work, IDEA, and Golden Passport

If we analyze Social Security Disability Insurance (SSDI) we see that, ostensibly, it is a disability-exclusive policy intended to provide income and benefit support for individuals who, because of a long term or permanent medical explanation, are unable to work (Berkowitz, 1989). Yet, in order to legitimately qualify, an individual must not only meet the internally located definition of disability advanced by the Social Security Administration in the U.S., but also must have previously contributed to social security, which one cannot do without working.

Because disability status and response under SSDI are internally situated, the process for legitimacy under SSDI places a medical or human service professional in the gate-keeping role. In order to be deemed legitimately disabled, a physician (or other specified professional depending on the explanatory diagnosis for not working) and several other evaluators determine one's fit with the legitimacy criteria. In order to qualify for benefits, an individual must prove disability legitimacy, which is not assured even if one meets the descriptive eligibility criteria. Explanations such as alcohol dependence, obesity, and chemical sensitivity (which in other policy arenas are explained as medical but often considered to be under one's personal control, or to be personally excessive, or even to be hypochondriacal) are not acceptable explanations for legitimate disability status under SSDI policy even though these explanatory conditions may be consistent with the descriptive outcome of long term or permanent impairment advanced under the policy guidelines. This hierarchy of acceptable conditions has been referred to as a disability pedigree to illustrate ranking of worth (DePoy & Gilson, 2004).

A careful examination of acceptable and unacceptable pedigree reveals SSDI policy values rooted in notions of personal responsibility, economic contribution, and charity. That is to say, an individual is legitimate only if he or she is not responsible for his or her inability to contribute to the economy. The meager income benefits hearken back to the historical charity model of disability in which disabled individuals were pitied enough for some altruism, but not sufficiently valued for support necessary to fully participate in their communities.

While supported on SSDI, individuals can receive Medicaid, which we have classified as embedded and explained by exterior circumstance (U.S. Department of Health and Human Services, 2006a), and in some cases Medicare, which we have coded as embedded and interiorly explained (U.S. Department of Health and Human Services, 2006b). Because Medicaid is the health insurance program for those in poverty it is not exclusive to disability but rather disability is embedded within it. We coded Medicaid as exterior because it locates poverty, not interior medical condition, as explanatory. Similarly, Medicare, health insurance for elders, is coded as embedded because it specifies disability within larger populations of elders. However, unlike Medicaid, the explanatory locus is interior, explained as embodied phenomena of advanced age or medical deviance.

Note that Medicare provides more substantial coverage than Medicaid, revealing the value hierarchy which favors assumed need on the basis of an uncontrollable circumstance. Until the passage of the Ticket to Work and Work Incentives Improvement Act in 1999 (TWIIA) (Wehman, 2000), an individual who returned to work would lose all benefits including health insurance. With this newly crafted legislation, health benefits and some income can continue as people attempt to return to work. We therefore located Ticket to Work under exterior explanations since policy rather than medical condition created the backdrop for this benefit. In any case, recipients of these safety net benefits are likely to be poor further splaying open the value foundation on remunerative work as policy driver in the U.S.

We also draw your attention to another issue related to health and income support benefits, regardless of their coding or explanatory stance. While benefits are most important for recipients of service, health insurance also pays providers for their work. Insurance also pays for the processes through which disabled individuals are qualified as legitimate and then afforded services under safety net policies. This activity comprises a large segment of the labor industry in the U.S. Thus, SSDI policy, while benefiting legitimate individuals who cannot earn, are purposive and valued payment systems for those who do earn. The economic value not only for direct policy beneficiaries but also for the labor market is a critically important element to consider in policy analysis and change (DePoy & Gilson, 2008). The Ticket to Work and Work Incentives Improvement Act of 1999 policy illustrates this point.

Before its passage, SSDI provided a disincentive for its beneficiaries to work since, as we mentioned previously, returning to work eliminated health insurance and income benefits. The value of these benefits often exceeded what a former SSDI recipient could earn in the job market. Thus, rather than enabling individuals to move away from public support, SSDI maintained recipients in the category of public welfare consumer. The Ticket to Work and Work Incentives Improvement Act was enacted to remediate this institutional mistake that rendered SSDI in conflict with its value base of economic self-sufficiency and personal responsibility.

SSDI provides an important exemplar of benefits to disabled non-workers. We contend that policies that establish and support job training and even specialized education fit under the content sub-category of access to opportunity for remunerative employment. Several of these disability-exclusive policies such as Individuals with Disabilities Education Act (IDEA) of 1990, 1997 and IDEA Regulations of 1999 (Pelka, 1997) and the Rehabilitation Act of 1973 (Barnartt & Scotch, 2001; Scotch, 2001) also fit under the category of material rights and benefits in that they provide specialized accommodations and resources on the basis of legitimate disability membership regardless of the accessibility of the employment or educational arena. These policies, based on nomothetic principles of group commonality, do not take into account the category members who may not want or need the resources provided on the basis of category membership alone.

Part of the quagmire in policies that address population categories is that rather than responding to descriptive need, category membership is the mediator and the locus for policy. Consider the disability-exclusive Golden Access Passport policy (National Parks Service, U.S. Department of the Interior, 2005) that allows disabled individuals to access national parks without paying. The policy, which assumes financial need on the basis of disability, is targeted at the broad category of disability. Thus, whether or not category members are financially needy, they obtain the privilege of free entrance, unlike individuals who have financial need but who are not legitimate members of the disability group. IDEA and disability-exclusive job training policies are similar in that they posit legitimacy for benefits on the basis of assumed need because an individual is legitimately qualified in a category, not because need for the resources and services under these policies is verified. On the other hand, given that disability exclusive specialized education and job training resources are not equivalent to those afforded to the typical population, the paradox of too many and too few resources under categorical policies continues (Stein, 2006).

The ADA and ADA Amendment Act of 2009

We now move to the ADA and ADA Amendment Act of 2009, a policy grouping that is designed to assert and advance legitimacy of citizenship, material benefits, and rights. As we address in Heuristic #6, protective disability-exclusive policy such as the ADA is both needed and extremely limited in promoting long-term equality of opportunity.

The Americans with Disabilities Act of 1990 (Scotch, 2001) and the 2009 ADA Amendment Act (together referred to as the ADA) comprise protective legislation that applies exclusively to disabled individuals. Similar to other protective legislation, the ADA prohibits discrimination on the basis of disability and asserts the guarantee of equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. Note that we locate the ADA in the interior explanations category of disability policy. Similar to policies that we have discussed previously, although the locus of the problem and its resolution are external, eligibility for protection under the ADA is determined by the pedigree of internal explanations for atypical characteristics. Look at the definition of who qualifies as legitimately disabled under the ADA:

> "[…An individual who has] a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment" (Americans with Disabilities Act, 1990, Definition section).

Because of its potential not only to provide opportunity where it did not exist, but also to support accommodations and thus special treatment, many groups with interior explanations for atypical function have attempted to seek coverage under the ADA. The court cases and decisions are the evidence of what is referred to as pedigree wars (DePoy & Gilson, 2004), as groups of individuals seek legitimate disability status in order to obtain rights that they may feel that they are otherwise denied. Under the ADA Amendment Act, the content of these cases is likely to shift from who qualifies, to what benefits will be afforded, to who meets the definition of disabled. Moreover, note that we locate the ADA under the policy genre of benefits and privileges for this reason. As we have introduced here, while disability-exclusive and other group-specific protective and non-discrimination policy has been an important method to advance inclusion and civil rights, its use as a long-term solution is problematic.

We acknowledge that many individuals with atypical characteristics, particularly those that are observable, have experienced overt and covert discrimination and oppression. As a disability-exclusive policy response, the ADA has made significant changes in access to the physical environment, the workplace, the communications and transportation systems, and the educational arena for many people who without the ADA would not be able to participate in those domains of daily life. Yet, as a permanent solution, protective policies, which on the surface appear sound, are riddled with value and social action conflicts (DePoy & Gilson, 2008). First, rather than assuring that policy for all citizens governs the rights of disability category members, the presence of the ADA implies that disabled individuals need specialized legislation layered on the policy that should already protect their rights. Second, the ADA stipulates that discriminatory practices such as environmental and telecommunication barriers need to be replaced with accessible structures in instances where cost would not be prohibitive. Thus, we see that the legitimate policy responses to discrimination are mediated by cost considerations that diminish civil rights and equality of opportunity of the very group that the policy is ostensibly designed to protect. Third, exactly who fits under ADA policy and what protections are afforded them are not clear; the policy's interpretation is thus subject to differential and context-embedded cultural, social, political, and economic values.

A Few Words on Disability-Implicit Policies

As we noted above and illustrated through the provision of examples in Table 1, many policies that do not directly address disability can be analyzed for their valuation or devaluation of descriptive diversity. Consider much of the OSHA legislation guiding workplace safety.

While not specific to atypical bodies, this legislation is designed to prevent injury that could result in disability and loss of gainful employment. Note the following excerpt:

> "To assure safe and healthful working conditions for working men and women; by authorizing enforcement of the standards developed under the Act; by assisting and encouraging the States in their efforts to assure safe and healthful working conditions; by providing for research, information, education, and training in the field of occupational safety and health; and for other purposes." (Occupational Safety and Health Act of 1970, "An Act" section, para. 1).

Axiologically, this excerpt reveals the positive value on maintenance of employment through enforcing standards that prevent the undesirables of illness, disability, and inability to work. Standards for typical bodily participation and protection include attention to ergonomics, air quality, elimination of conditions that are explained by exposure to toxic chemicals, and so forth.

Similarly, seat belt laws, while not disability-explicit, are designed not only to prevent fatality, but to decrease disability explained by catastrophic injuries such traumatic brain injury, loss of limbs, and so forth. While we are not criticizing the protective nature of these policies and their essential place in civil societies, we bring attention to an alternative meaning for the purposes of policy analysis. As we noted, policies are more than their verbiage. By valuing "healthy lifestyle," it is not only defined but its opposite can be interpreted as de-valuation of what is "not healthy" and typically functional in our current contextual environments. As example, permanent injury explanations for atypical description as well as the asserted attribution of excessive cost are often decried. These policies speak to prevention through enforcement of built and behavioral standards rather than to response of the inevitability of injury and illness that will occur for some proportion of the population.

Historically, numerous laws in the U.S. have been enacted to deny immigration to individuals with interior explanations that qualify as disability. According to Jaeger and Bowman (2005), these laws, while not explicit, still persist in policies that limit citizen benefits to aliens with "pre-existing conditions." Once again, the devaluation of atypical bodies and the utilitarian scare of excessive expenditure, depicted as Heuristic #6, are evident in these disability-implicit policies.

Conclusions

Framing disability-exclusive and embedded policy in the U.S. from a population subcategory specific approach has been both a blessing and a curse. Disability policy has provided necessary safety nets, benefits, and efforts for promoting opportunity for participation in work, community life, and the economy. However, the maintenance of population-specific policy has the danger of perpetuating separation and differential treatment in the long term. Disability-implicit policies, while not rhetorically segregated, obfuscate axiological foundations and essentialist assumptions about disability. We suggest that because of its structure and focus on values and purpose as the drivers for policy, Explanatory Legitimacy Theory provides the framework through which necessary policy change can be informed and enacted. As we move into the 21st century, we face the challenges and opportunities of an expansive global and virtual environment. We are met with the juxtaposition of diverse worldviews and experiences while we are gifted with the thinking and action tools to operationalize the values of tolerance and symmetry of opportunity (DePoy & Gilson, 2008). Rethinking disability policy (and other population-categorical policies) on a foundation of celebrating diversity can move us towards policy that creates universal rights, resources, and privileges on the basis of human description and need, rather than on tacit and nomothetic assumptions about individual embodied worth. Our charge is to analyze, rethink, and implement policies that shape our world as one that is welcoming of all.

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Book Reviews

Title: *Blindness and the Multi-Sensorial City*

Editors: Patrick Devlieger, Frank Renders, Hubert Froyen, and Kristel Wildiers

Publisher: Antwerp: Garant, 2006.

ISBN: 90-441-1739-4, 372 pages

Cost: $97.50 USD order@coronetbooks.com

Reviewer: Michael L. Dorn

Accepting the call of the European Disability Forum, the city of Leuven, Belgium and its University (Katholieke Universiteit Leuven in Dutch) embarked on a "modest project" that grew larger and deeper in time, to consider the experiences of persons with disabilities in historic cities and find ways to achieve greater levels of inclusion (p. 11). Led by an innovative interdisciplinary team comprised of anthropologists, architects and planners, the city engaged in a deliberative process in preparation for the 2003 European Year of Persons with Disabilities. In the interests of building upon existing strengths and addressing a population all too often neglected in academic discussions of universal design, the stakeholders decided to focus on the experiences of blind people and those with visual impairments. In the book that documents this immense project, *Blindness and the Multi-Sensorial City*, editors Devlieger, Renders, Froyen and Wildiers draw together the insights of a stellar group of interdisciplinary scholars and activists—anthropologists and geographers, psychologists, designers and architects, employees of the World Bank, the Leuven government, and volunteers with advocacy groups. The resulting volume is a multi-sensory joy. It contains eighteen essays and nearly 30 authors, ample provision for color photography, as well as an enclosed digital version on CD.

The book is divided into eight sections, two chapters typically per section, on themes such as mobility, tactility, competent tourism, education, and spatial analysis. Chapter by chapter, readers consider a variety of different theoretical and practical ways of re-conceiving or revising the relationship between the blind person and the historical city. The largest of the eight sections in the book is devoted to the studies and projects of multi-sensory design. Here, four different visions by architects or firms are represented. The visionaries are Peter Howell and Julia Ionides of the Dog Rose Trust (Ludlow, UK); Marta Dischinger (Florianópolis, Brazil); Seema Malik of Avanish K. Malhotra Architects (Manhattan, New York); and Vinko Penezic and Krešimir Rogina of Penezic & Rogina Architects (Zagreb, Croatia). The works presented in these chapters run the gamut from audio and tactile interpretations of national historic treasures (Dog Rose Trust), to analyses of 'spatial mental representation' that offer new strategies for universal design (Dischinger, and Malik), to a critical exploration of the new digital environment that offers a glimpse of a future audio-tactile culture (Penezic & Rogina).

There is much to recommend this book. The editors express a firm dedication to cross-cultural exploration of the environmental conditioning of disability experience. The twenty-seven different contributors for the volume draw on their unique cultural viewpoints as well, hailing from across Europe, the United States, Brazil, and Australia. The passion of shared exploration can be felt throughout the work, as high theory is joined by pragmatic reports on workshops and tangible outcomes, including a recently published guide to the city of Leuven. Sometimes this can result in a clash of international perspectives, such as differences over the choice of terminology between the English ("disability") and the Dutch ("handicap"). In other places this can result in a minute investigation of particular environments, as in David Mellaerts' chapter on 'Hearing, smelling, touching and moving as an alternative way of beholding,' a process of discovery where visually impaired and able-bodied people collaborated in writing a multi-sensorial text *Leuven Horen en*

Voelen (Hearing and Touching Leuven), selecting and producing tactile plates, and developing the city's audio guide.

The overall effect of reading the book is transformative, challenging Westerners in general, and architects and designers in particular, to reconsider definitions of rationality and their ocularocentric focus on visual perception in common public spaces like museums. Laying the groundwork for these alternative imaginings and experiencings, a select group of designers and architects share projects that explore avenues for insight and offer keys to recognizing and enhancing non-visual sources of information. This book offers a generous range of examples of the sort of engaged normative research-and-education that can transform lives. These engaged scholars offer themselves as cultural brokers for the rest of us. The question remains: will other cities follow Leuven's lead and move beyond the dialectic of historic city vs. blind visitor to consider the already available means for making contact and constructing new spaces and encounters?

Blindness and the Multi-Sensorial City offers a stimulating introduction to the connections between disability studies and sensual cultural geography and is recommended for social science and humanities scholars who are interested in engaging in cooperative projects at urban redesign, as well as planners, city administrators, and designers. For scholars interested in learning more about the history, anthropology and psychology of non-visual perception, the references alone are worth the price of admission. The publisher Garant is to be commended for inclusion of the entire text on digital CD, which is unfortunately still all-too-rare for publications in this field.

Michael L. Dorn, Ph.D., Clinical Assistant Professor of Urban Education, Temple University, holds a split appointment between the Department of Educational Leadership and the Institute on Disabilities at Temple University. A cultural geographer by training, Mike has served as guest editor with Deborah Metzel of two special issues of *Disability Studies Quarterly* on Disability Geography, and is currently one of the editors of the blog Disability Studies, Temple U., http://disstud.blogspot.com

Title: *Working and Caring for a Child with Chronic Illness: Disconnected and Doing it All*

Author: Margaret H. Vickers, University of Western Sydney

Publisher: New York: Palgrave Macmillan, 2006

Cloth-bound only, ISBN: 1-4039-9767-5, 225 pages

Cost: $55.00 USD

Reviewed by: J. Gary Linn, Ph.D.

Margaret Vickers, in her monograph *Working and Caring for a Child with Chronic Illness: Disconnected and Doing it All*, describes the lived experience of a little studied group—working women who have chronically ill children. This path-breaking work appropriately targets students, researchers, and professionals in health care management, gender studies, social policy, and the sociology of the family.

Through in-depth interviews, poems, and vignettes, Vickers provides richly detailed descriptions and analyses of the relationships, issues, and feelings that define these women. By reading this monograph, the health care manager will be sensitized to their time constraints and psycho-social stress, the researcher in gender studies and health policy will learn about their often unmet needs for social and material support, and the student in family sociology will develop an understanding of how they struggle with stigma and role strain on a daily basis.

Vickers' pilot study of working women with chronically ill children sets the demographic and relational parameters for her own (and others) qualitative and quantitative research on this group. This is the value of an expertly done exploratory study of a problem and group for which we essentially have no data; based upon the valuable and provocative findings of this inquiry, Vickers was able to obtain a substantial grant from the Australian government to expand her work on working mothers with chronic illness.

Readers will find this monograph interesting both for its findings and method. In rich and intimate detail, Vickers presents a global picture of working women with chronically ill children. We come to know the relational causes of their role strain; they have young children with many special needs, demanding professional work obligations, and (sometimes) indifferent or nonexistent husbands/partners. We are given a lens to view their personal anguish and frustration. Further, we are walked through the meticulous process of action-related qualitative research. Vickers gives a thorough explanation of how she obtained her data through repeated in-depth interviews, poetry, and the use of constructed vignettes. Finally, we learn about the empowerment and successes of some of the women with chronically ill children who participated in this process. Nevertheless, there are some acknowledged and unacknowledged limitations to this study.

The purposefully selected sample of nine, which in the initial in-depth interviews provides a wide range of lived experience of women in the workforce with chronically ill children, dwindles to two at the final stage of the research. This does not compromise the validity of the study because most of the reported findings are from the initial interviews. I am confident in her larger funded investigation, Vickers will be able to increase her sample size to at least 25 or 30 participants and have sufficient paid staff to stay in touch so most of them will not be lost over time. This will be important if she wants to have a robust test of her action theory, which requires feedback from participants after they have been given potentially helpful information and support "early on" in the research process.

There are no women in this study whose husbands/male partners fully share in the care of the chronically ill (and other) children. If Vickers seeks to provide a representative account of the lived experience of working women with chronically ill children, she needs to also sample couples that have more egalitarian childcare role sharing. Surely, in an advanced post-industrial society like Australia, they are a substantial group whose views should be reported.

The external validity of Vickers' work may be compromised somewhat because her study was done in a culturally homogeneous society (Australia) where there is a high level of social services and a long tradition of progressive legislation in support of workers. The United States, with a culturally more diverse population, and (despite Family Leave legislation) a work force that in many cases has few protections or supports for parents with chronically ill children, might have a wider range of experiences. Specifically, higher status women who work in large public or private organizations would be covered by the Family Leave Act and often have resources to access services needed to care for a chronically ill child (even if they have an uncooperative partner), while women working in small businesses and low level clerical (and other) positions would have few options and be potentially more stressed as a result of having to fulfill work and childcare obligations.

Two other limitations of Vickers' monograph are that it is only available in a more expensive cloth-bound edition in standard font. Optimally, there would a large print inexpensive soft cover copy on the market. Nevertheless, because this book makes an important contribution to knowledge about an increasingly important group—working women with chronically ill children—I recommend it with high enthusiasm.

J. Gary Linn is Professor, School of Nursing and Center for Health Research at Tennessee State University. He may be contacted at: jlinn87844@aol.com

Title: *Frontiers of Justice: Disability, Nationality, Species Membership*

Author: Martha C. Nussbaum

Publisher: Cambridge: Harvard, 2007

ISBN: Paper 978-0674024106, 512 pages

Cost: Available at amazon.com for $17.05 USD (retail $18.95)

Reviewer: Carrie Griffin Basas, J.D.

In her latest work, Frontiers of Justice: Disability, Nationality, Species Membership, Martha Nussbaum argues that political philosophers have left the situations of people with disabilities (specifically, those with mental impairments), non-human animals, and people in developing nations largely unresolved. Their theoretical approaches do not build-in the perspectives of these groups because the approaches are based on exclusionary models of social contract. Social contract theory assumes that two equally positioned, able-bodied people are willing to act in each other's best interests because they expect mutual advantage and reciprocity. Nussbaum advances a "capabilities approach," introduced by Amartya Sen in economics. Unlike its name, which connotes function, the capabilities approach focuses on a list of ten core opportunities or freedoms that all people should have and be able to experience; she argues "that all of them are implicit in the idea of a life worthy of human dignity" (p. 70). The ten opportunities include life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; other species; play; and control over one's environment (pp. 76-77). Nussbaum regards this project as "fully universal" (p. 78) and an "essay in practical philosophy" (p. 4).

This review focuses on what Nussbaum has to offer to the disability rights community. At times, her prose is dense with terms of art from social theory and philosophy. Many community-based advocates will probably choose to skim sections where she situates her theory in relation to Kant, Rawls, and other philosophers. Readers with philosophy backgrounds or interests, however, may find these sections more engaging.

What Nussbaum has to say about disability closely resembles the socio-cultural model known to disability advocates and theorists. Many of her examples of inclusion are familiar ones based on concepts of universal design, social integration, and equal access. In situations where people with mental impairments are not able to independently take advantage of Nussbaum's identified opportunities, she advocates a respectful guardianship system, inspired by European models. Under this system, people with disabilities are assisted in exercising these rights, if they would like.

Nussbaum highlights the "burdens" (p. 222)—an unfortunate word choice—of caregivers of people with disabilities and the obstacles these individuals have. Her position is they have been as forgotten by social theory models as people with disabilities themselves. She describes the relationship between disability awareness and feminist theory, and emphasizes that societal barriers encountered by disabled people are political, not merely personal issues to be worked out among caregivers (largely female) and family members. In this discussion, she gives a voice to caregivers, but she also may be shortchanging the experiences of people with disabilities. Most of her examples focus on parents of mentally disabled children; her tone is sympathetic, compassionate, and ardent. The examples are told mostly from the perspectives of the parents and caregivers and make more limited attempts to frame the experiences from the perspective of the people with the mental disabilities.

Nussbaum's book may generate some negative reactions from people with disabilities, particularly those working as advocates. For example, she mentions that even though the productivity of some people with disabilities will exceed the costs of accommodating them, society struggles to find a basis (e.g., financial returns, moral good, civil rights) for accommodating people with disabilities at all. "None of the three [mentally disabled people] is likely to be economically productive in a way that even begins to compensate society for the expense it incurs in educating them" (p. 128). Financial sense will not be enough to justify it, according to Nussbaum, but justice and "human dignity" should be (p. 118).

Also in a move that may upset some advocates, she writes that people in a persistent vegetative state are no longer people and therefore fall outside the capabilities approach:

"In other words, we say of . . . a permanent vegetative state of a (former) human being that this just is not a human life at all, in any meaningful way, because possibilities of thought, perception, attachment, and so on are irrevocably cut off. . . . (And we do not say this if any random one of the capabilities is cut off: it would have to be a group of them, sufficiently significant to constitute the death of anything like a characteristic human form of life. The person in a persistent vegetative condition and the anencephalic child would be examples)" (p. 181).

Even with its missteps, this book will be a welcome arrival for people interested in the intersection of disability rights, animal rights, and globalization. While Nussbaum's capabilities approach may be a departure from, or a profound extension of, existing political theory, its concepts are not new to the disability rights movement. She has articulated a list of activities and accesses that many people with disabilities seek without knowing they fall under a capabilities approach:

"The core liberal goals seem even more urgently important for people with mental impairments than for "normals," because it is their individuality, not that of 'normals,' that is persistently denied; it is their freedom that has been characteristically abridged through prejudice, lack of education, and lack of social support; and it is their equal entitlement to the prerequisites of a flourishing life that has been ignored, as societies pursue impoverished understandings of the benefits and burdens of social cooperation" (p. 222).

In this way, the book's most powerful effects may be found among political scientists and social theorists with little exposure to disability. In "mainstreaming" disability to this audience, Nussbaum has expanded the dialogue about disability in looking at how societies and other communities are formed, shaped, and sustained. She moves disability from the realm of charity and compassion to that of justice.

Carrie Basas (Harvard 2002), Assistant Professor, University of Tulsa College of Law, teaches criminal law, legal ethics, and disability rights at the University of Tulsa College of Law. She may be contacted at: carrie-basas@utulsa.edu

Title: *Waking: A Memoir of Trauma and Transcendence*

Author: Matthew Sanford

Published: New York: Rodale, 2006

Cost: $14.95 USD

ISBN: 13-978-1594868450, 253 pages

Reviewed by: Steven E. Brown

In the first chapter of *Waking*, Matthew Sanford writes, "Some people are born with a smile on their face, and I am one of them. I do not mean this metaphorically. I literally mean that my mouth does not seem to possess the ability to form a frown. . . . After all that has happened, I am grateful for this fact" (p. 3).

At the age of thirteen, Sanford's family was in a car accident. His father and his older sister died. He was thrown from the vehicle to awaken in a hospital several days later paralyzed from the chest down. As readers we know from the outset, there is a happy ending to this story. We know this from the synopsis of the book and from the author himself, who in the first pages introduces us to his family—a wife and children—and to concepts of healing. We also know there is a long journey from pain and agony to get to *Waking*.

On the initial page we learn the Minnesota-based Sanford separated his mind from his body while experiencing traumas after his accident. "Leaving my body became a survival skill" (p. xv).

In the first of the book's three sections, Sanford describes his trauma and pain. He recalls what he can dredge up in his memory about the accident and consequent hospitalizations. He lived not only with pain of his disabling condition, but with the agony of knowing he survived a horrendous event that rendered his family asunder. He guides us through these experiences.

In the final two sections he leads readers through his emergence from his life of pain and despair. He begins to explore other ways to move through the world, from his wheelchair. This journey leads him to a yoga teacher. Never having worked with a paralyzed person presented challenges to Sanford's mentor and together they figured out how to apply yoga in his situation.

Sanford found yoga to be his personal method to connect with the wider universe and to heal, while he remains paralyzed. In 2001, he founded Mind Body Solutions, a non-profit charitable organization, dedicated to the idea minds and bodies work better together. Near the end of the book, Sanford writes:

> If nothing else, my life has taught me one thing. The mind and body that I have are the only mind and body that I have. They deserve my attention. And when I give it, I receive so much more in return (p. 222).

This well-written autobiography is one of the first to explore disability and healing from a perspective that disability is not an inherently negative condition and healing does not mean walking away from a wheelchair. It deserves a wide audience.

Steven E. Brown is Associate Professor at the Center on Disability Studies at the University of Hawai'i and an *RDS* editor.

Title: *Disabling Pedagogy Power, Politics, and Deaf Education*

Author: Linda Komesaroff

Publisher: Washington, DC: Gallaudet University Press, 2008

ISBN: Paper 1-56368-361-X, 978-1-56368-361-9, 139 pages

Cost: $45.00 USD

Reviewer: Jan-Kåre Breivik

Disabling Pedagogy is a must-read for everyone engaged in deaf education--be it teachers of the deaf, administrators and politicians, parents of deaf children, or deaf adults--throughout the world. The book provides strong arguments in favour of bilingual education with a strong focus on sign language as a deaf person's first and most important language.

There have been plenty of references in the literature to the low educational level and poor literacy achievement most deaf students have attained. This under-achievement has been differently understood among researchers and educators. One view blames the "victim" by pointing to the failure of deaf children as the result of deafness, claiming hearing loss as the main barrier to learning. Within this "tradition" the solution is to provide more of the stuff that has caused much of the problem in the first place: speech training, better hearing aids, cochlear implants, and a "stay-away-from-sign-language" attitude. If visual techniques are involved they serve as a basically oralist attitude and educational strategy (i.e., Signed English and so called Total Communication).

A contrary view, the one Komesaroff embraces, emphasizes the way in which deaf students have been educated, pointing to pedagogy that is disabling, rather than any defect in the child as the cause for educational failure. In support of this view, Komesaroff points to a large body of research and practice on the benefits of using sign language as the first language and as the necessary language of instruction for deaf children.

Komesaroff, a senior lecturer at Deakin University, in Melbourne, Australia, has also edited *Surgical Consent: Bioethics and Cochlear Implantation* (Gallaudet University Press, 2007) one of the best books available on Cochlear Implants.

In *Disabling Pedagogy* she backs-up strong arguments by presenting her own research. She establishes a deep and situated account of deaf education in Australia by combining interviews with teachers, deaf leaders, and parents, with ethnographic observation in school settings. The accounts, which also include court cases, however, are quite depressive reading. The phonocentric (or audist) position of dominant groups and institutions and their influence on educational policy and practice have mostly resulted in failure and disempowerment. In order to acquire more positive and future-oriented understanding, Komesaroff subscribes to a research strategy that she coins "politically active research."

"Systems do not usually change at the top" (p. 116) she states, and since language and education are "bound up with issues of power" (p. 115), research cannot simply do with neutral rapport. In her own active and politically informed research she shows (partly by means of her active involvement) how attitudes and practice can change when parents and teachers get the chance to see and experience what a different educational policy can do for deaf children. To substantiate her conclusions she also draws upon experience from other countries (Scandinavian mostly) where bilingual educational schemes have been implemented.

As a Norwegian anthropologist with some knowledge of this field, I highly recommend the book. But I have to say (in line with Komesaroff) I am not too optimistic for the future of deaf education. Even in the Scandinavian countries where the different sign languages have been recognized and where bilingual education has been politically confirmed, the tendencies to go in the other direction are quite massive (normalization, mainstreaming, routine cochlear implantation of small children). However, this book is a central contribution to the field, and provides grounded arguments for a better educational policy and for claiming access to sign language as a human right for deaf kids.

Jan-Kåre Breivik is a senior researcher within social anthropology at the Rokkan Centre for Social Science Studies, University of Bergen, Norway. In 2005 he published the monograph *Deaf Identities in the Making: Local Lives, Transnational Connections* (Gallaudet University Press). E-mail: jan.breivik@rokkan.uib.no

Title: *The Human Right to Language: Communication Access for Deaf Children*

Author: Lawrence M. Siegel

Publisher: Washington, DC: Gallaudet University Press, 2008

ISBN: Paper 1-56368-366-0, 978-1-56368-366-4, 164 pages

Cost: $49.95 USD

Reviewer: Jan-Kåre Breivik

In 1982, the United States Supreme Court ruled against Amy Rowley, a deaf six-year-old, who was seeking the right to sign language interpretation in her public school classroom. Siegel, founder and director of the National Deaf Education Project and a special education attorney in San Francisco, disagrees with this decision since it denies deaf and hard of hearing children what virtually every other American child takes for granted: the right to receive and express thought and to cultivate his or her preferred language in school. This is a situation impossible to accept, and Siegel therefore contends the U.S. Constitution should protect every deaf and hard of hearing child's right to communication and language as part of an individual's right to freedom and equality. Furthermore, he insists with force and solid documentation that this is a basic human rights issue. In this, he is in line with Linda Komesaroff's argument and points of view in *Disabling Pedagogy*. This is, however, a reading that is as equally depressive as Komesaroff's book, since the Rowley decision remains "the law of the land," as Siegel puts it. But how can this be, and what can be done? These are the main questions this book raises and partly answers.

The book is written in a highly accessible style and introduces the reader to the grave injustice deaf and hard of hearing children are exposed to in the U.S. school system. Siegel argues and documents with force that when a deaf or hard of hearing child sits alone in a crowded classroom and is unable to access the rich and varied communication around her, the child is denied any chance for success in life.

A clue for understanding the lack of access to communication and language is that the common notion of a right to "speech" is too frequently interpreted narrowly as the right to use one's voice. In this rather phonocentric atmosphere, it is hard to get through with the broader understanding of the right to receive and transmit information in all ways, including visually through sign language.

Siegel reveals there are no judicial decisions or laws that recognize this missing right, and he offers a legal and constitutional strategy for change. By providing many examples of deaf children with inadequate communication access in school, he makes a compelling case for changing the status quo. One can, as Siegel insists, hope things will change as they did for African Americans through the well known *Brown v. Board of Education* court case in 1954. Before 1954, "the law of the land" was thoroughly racist and segregationist and considered "natural" and "normal." And if that status quo could be questioned and finally overcome, can the same happen for deaf and hard of hearing children in school?

The strength of Siegel's *The Human Right to Language* is that it challenges the U.S. legal system but with a potential global scope. I would recommend reading it together with *Disabling Pedagogy* because the two books complement one another in a rather empowering way. Both give reasons for fighting for changes both in the legal and the educational system. It seems plausible that both strategies must be pursued together if any major change shall be attained.

Jan-Kåre Breivik is a senior researcher within social anthropology at the Rokkan Centre for Social Science Studies, University of Bergen, Norway. In 2005 he published the monograph; *Deaf Identities in the Making: Local Lives, Transnational Connections* (Gallaudet University Press). E-mail: jan.breivik@rokkan.uib.no

Disability Studies Dissertation Abstracts

*** Editor's Note: This is a new section of RDS courtesy of Jonathan Erlen of the University of Pittsburgh. Abstracts listed below are selected from a full list of disability-related dissertation abstracts updated quarterly. The full list is available at: http://www.hsls.pitt.edu/guides/histmed/researchresources/dissertations/index_html.

Attitudes and willingness of California community college public safety (Police, fire and emergency medical services) faculty to provide accommodations for students with learning disabilities. Malangko, Mark C.. Proquest Dissertations And Theses 2008. Section 0035, Part 0514 136 pages; [Ed.D. dissertation].United States -- California: University of California, Santa Barbara; 2008. Publication Number: AAT 3323700.

Cultural worlds of d/Deaf children in school. Valente, Joseph Michael. Proquest Dissertations And Theses 2008. Section 0010, Part 0518 172 pages; [Ph.D. dissertation].United States -- Arizona: Arizona State University; 2008. Publication Number: AAT 3321177.

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Exploration of siblings' explanatory models of Autism. Carter, Faye Isobel. Proquest Dissertations And Theses 2008. Section 0031, Part 0529 202 pages; [Ph.D. dissertation].United States -- California: University of California, Los Angeles; 2008. Publication Number: AAT 3322093.

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A sibling support group for siblings of children with autism. Perez, Tracy. Proquest Dissertations And Theses 2008. Section 1355, Part 0622 125 pages; [Psy.D. dissertation].United States -- Florida: Carlos Albizu University; 2008. Publication Number: AAT 3319751.

Perceptions of sibling relationship quality: Differences between deaf- hearing dyads and hearing-hearing dyads. Dardeen, Kelly Renee. Proquest Dissertations And Theses 2008. Section 0094, Part 0451 81 pages; [Ph.D. dissertation].United States -- Indiana: Indiana State University; 2008. Publication Number: AAT 3322202.

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About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of Hawai'i at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai'i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai'i, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

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