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## Editorial: Learning Stuff We Don't Know

Megan A. Conway, Ph.D.  
RDS Managing Editor

With all due humility, it's hard for me to learn that I don't know something, especially something about disability. My husband says that's because I graduated from Berkeley. Needless to say, he didn't. But a recent experience organizing a panel of experts for my online introductory Disability and Diversity Studies course gave me a good look at my own ignorance.

It started out as a really great idea to put together a panel of people with different kinds of disabilities, from different cultural backgrounds, to talk to my class about multiculturalism. The students have read about multiculturalism. I've talked about multiculturalism. But I thought it would be good if they could hear it straight from the source. The article in this issue by Hulgin, O'Connor, Fitch and Gutsell on Disability Studies Pedagogy points out the value of these sorts of experiences for students who are being asked to critically examine new ideas.

Also, I am of the opinion that "experts", many of whom do not actually have disabilities, often get paid far too much to offer their expert advice about disability, backed by lengthy citations and references, when a two minute conversation with a person with a disability would help people figure everything out. If this sounds strange coming from the Editor of an academic journal, so be it. I just wanted to recognize the guy who provides the two-minute conversation.

I began making enquiries of various colleagues and colleagues of colleagues, looking for that perfect mix of crippling and culturalness that would truly impress upon my impressionable students the nuances, richness and complexities of a multicultural society. In my case, I got a good dose of the complexities.

There was the diversity of communication needs of my panelists. Now being deaf-blind myself, I am no stranger to communication diversity and in fact consider myself to be quite the little "expert" when it comes to matters of communication. I had one panelist who was deaf-blind, but who has some vision and hearing, so I thought Real Time Captioning would be a great accommodation. Another panelist was Deaf. Hey, great, kill two birds with one stone. In fact, I figured we could all type back and forth instead of talking to give the students a sense of what it's like to experience a lecture without sound. So I was shocked when the Deaf panelist told me, "Sorry but my English is not that great and I would really prefer to use a sign language interpreter." And then another panelist said, "I would love to type everything but I have limited use of my hands."

So I arranged for sign language interpretation for the Deaf panelist. And I arranged for a student to assist the other panelist with navigating the keyboard. Then the deaf-blind guy said he couldn't see the captions.

Luckily the deaf-blind guy had a friend who could assist him. And it turns out the captioning was needed after all because another one of the panelists spoke English as a Second Language. Unfortunately for me, Dr. Cultural Sensitivity, his name and his country of origin have a lot of Y's and V's and Z's all next to each other, so I introduced him as something like "Yes-is-kee Ze-sis-kee from Ku-ku-staskee". Then I introduced the deaf-blind guy as being "of the Native American People" and

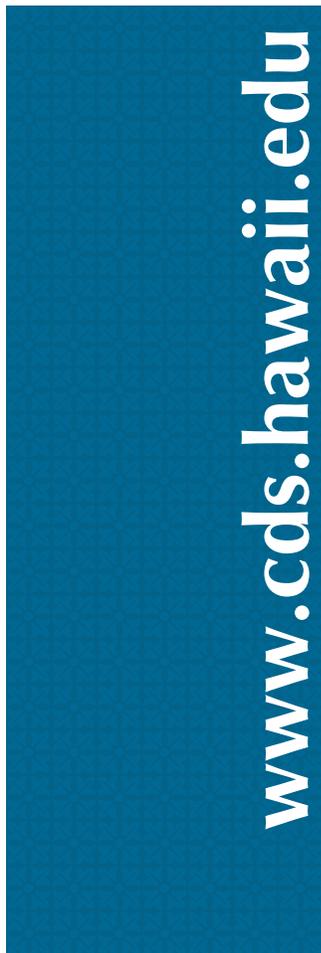
he said, “I’m not of any group of people. I just am. And by the way, I don’t think of myself as being ‘deaf-blind’.”

In the end I could feel really good about meeting the individual needs of all of my panelists. And they were all terrific speakers. And the class got a lot out of their presentations.

But inside, you know where that little spark of pride lurks for being the Disabled Woman Who Preaches Disabled People as the Experts, there is also a little flicker of shame. Because although I tell every one of my students that the key to changing our views about disability and diversity is to admit that what we think we know may not be the truth, I thought I knew everything. And then I had to learn stuff I didn’t know. And that was hard.



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# Forum: Disability And Employment

## Introduction

Stephanie Patterson

Pamela Block, Ph.D.

Niel Bohrs' famous quote "Nothing exists until it is measured" (as cited in Ross, 1997) refers to quantum physics, but it can also be applied to the history of disability and employment. Scholarly information concerning this history is almost nonexistent. While cursory examination of employment issues may be included in discussions about past social movements and legislation, these discourses are often anecdotal and always secondary to the main topic. With few exceptions (studies on freak shows, for example) it appears that scholarly, historical pieces specifically about disabled people as workers are rare.

Without readily available, factual accounts on the experiences of disabled workers throughout the centuries, it can appear, to those with and without disability, that "disability" and "employment" are mutually exclusive terms. An example of such an assumption in the United States is shown by current language usage separating the images of "disability" and "work." A useless car in need of repair is labeled "disabled"; a "disabled" computer has been altered to prevent it from working.

But having a disability does not automatically and inherently bar a person from the world of work. Through research, we have discovered that people with disability have always been members of worldwide workforces. To address this under-represented aspect of disability studies and endeavor to negate the resulting assumptions, this Forum initiates the task of compiling information about the historical experiences of disabled workers. It is neither an attempt to negate or minimize the concerns that unemployed disabled people currently experience and have experienced in the past; nor infer that employment discrimination did not and does not exist. We simply hold the belief that in order to accurately portray the experiences of people with disability, it is important to collect accounts of their careers and work enterprises.

Our Forum begins with "A Historical Overview of Disability and Employment in the United States (1600 to 1950)." Through the centuries, disabled people have been important members of the US workforce, adding their skills, unique abilities and hard labor with able-bodied workers to manifest the American dream. Although, due to the limitations set by this journal, a relatively scant amount of the available data has been included, this article initiates the task of telling some important stories. The time span was chosen arbitrarily in an attempt to provide the broadest overview. Examples were used that best illustrated the chronological periods addressed and are by no means exhaustive. Much remains to be told through future research efforts.

England's Elizabethan Poor Laws were written in the 1600's and their purview transferred to the American colonies. The distinction they made between the deserving and undeserving poor based on the ability and willingness to work continues to influence the consciousness of western societies. Martin Atherton's "Deserving of Charity or Deserving of Better?: The Continuing Legacy of the 1834 Poor Law Amendment Act for Britain's Deaf Population" discusses this legislation's effect on deaf employees in the United Kingdom today.

The significant historical experiences of African Americans with disability are in the process of being chronicled. For those enslaved on plantations, information exists in the records kept by landowners. Dea Boster uses these and other sources to write about tasks performed by disabled slaves and how

they were treated in “Useless”: Disability, Slave Labor, and Contradiction on Antebellum Southern Plantations.”

Existing histories were created by telling the stories of individual citizens. From such a lens, the accounts of disability and employment are colorful, varied and full of accomplishment. From a biographical perspective, these life stories are an important component of our historical research and add personality and resonance to our endeavor. For this reason, our Forum includes “Electioneering and Activism at the Turn of the Century and the Politics of Disablement: The Legacy of E.T. Kingsley (1853-1929), Ravi Malhotra’s research on the life of a largely unknown, but significant, North American political figure.

Considerable legislation and social attention has been afforded veterans who have incurred disability as a result of military service. Government initiatives throughout the world have included vocational rehabilitation, education and employment programs. Jeff Grischow’s article “Disability and Rehabilitation in Late Colonial Ghana” discusses the British government’s 1940’s Social Orthopedics Program, an attempt to retrain disabled soldiers and reintegrate them into the workforce.

As often with scholarly undertakings, we have many hopes for this Forum. The first is that it has the potential to effect the way people with disability perceive themselves and transform the way they are perceived by others. The second is that these accounts demonstrate that, in many cases, being disabled does not have to result in being unemployed. Lastly, that this collection piques the interest and curiosity of scholars and encourages them to gather further information, ushering in a new era of disability research – one that records the rich and varied legacy of the work-related accomplishments of people with disability.

**Stephanie Patterson** is a Clinical Assistant Professor at Stony Brook University. She has a Masters in liberal studies with a concentration in disability and employment and has actively worked in the field of disability and employment for over 15 years. She is a staunch member of the campus President’s ADA Advisory Committee and is Chair of the ADA Awareness Subcommittee. Currently, she teaches a course she created entitled Disability and Employment for the Disability Studies concentration and Professional Ethics in Health Care for the Health Science program.

**Pamela Block, Ph.D.** is an Associate Professor at Stony Brook University in the School of Health Technology and Management. She completed a doctorate in cultural anthropology at Duke University in 1997. Her dissertation research addressed historical intersections of gender, race, class, sexuality, and disability in Brazil and the United States. She was on the Board of Directors of the Society for Disability Studies from 2007-2011, serving as Vice President in 2008-2009 and President in 2009-2010.

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# A Historical Overview of Disability and Employment in the United States, 1600 to 1950

**Stephanie Patterson**  
**Stony Brook University**

FORUM

**Abstract:** Through a preliminary review of existing literature and archival source materials, this brief overview begins the task of compiling existing data about the history of disability and employment in the United States. A chronological framework is used that includes employment-related phenomena. The major topics covered are pre-industrial rural life, post-industrial work opportunities and the government's response to the employment needs of disabled veterans. In addition, due to relevance to the topic, there is a brief mention of freak shows and the dawning disability rights movement after WWI.

**Key Words:** Disability, labor, US history

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

## Introduction

"If anyone will not work, let him not eat."  
2 Thessalonians 3:10 (The Holy Bible)

Communities thrive when individuals band together, pooling skills and talents, to empower the group. Parents teach children this concept through assigning chores, and teachers reinforce it through group projects. The expectation that individuals must contribute, perform labor in some way, in order to be viable members of society can be found in both developed nations and in tribal cultures. Some national identities were developed on the foundation that citizens excelled at productivity and competition. For example, from the beginning of the United States (US) as a republic, male citizens viewed themselves as being "supremely normal" by being physically fit and able to fully participate in free-enterprise capitalism (Thomson, 1997, p. 42).

This connection of worth to the community and one's ability to work continues today and has as far-reaching consequences for people with disability<sup>1</sup> as those without. Research indicates that through the centuries, disabled people have been important members of the United States workforce, adding their skills, unique abilities, and hard labor alongside able-bodied worker's to manifest "the American Dream." Yet, just as minority and ethnic groups have raised the issue of having their histories barred from textbooks (Scharrer, 2010), this is no less true for records about the careers of disabled people.

Historically, countless people with disability have joined, maintained and strengthened the ranks of the United States labor pool. Literature and archival materials exist representing disabled people as productive members of their community's workforce, but this information has never been systematically compiled, leaving many stories untold. As noted in the Handbook of Disability Studies, there are three key problems to writing disability history – 1) the lack of primary sources, 2) most of the material that is available is written from the perspective of service providers and 3) much information is disability-specific rather than covering a broad spectrum of disabilities (Albrecht, 2001). All three of these factors were relevant to the endeavor of writing this article. In addition, pertinent information had to be painstakingly gleaned out of works devoted to other topics, much like a miner sifts through dirt for gold.

This effort begins the process of consolidating existing information into one document for easier reference. The selected time periods were chosen arbitrarily in an attempt to "start somewhere" to provide an overview. The illustrative examples were chosen for interest and readability.

ity and are, by no means, exhaustive. Due to the space limits placed on this particular paper, it can only indicate the scope of research needed, not accomplish the task.

### **Pre- Industrial Work Opportunities**

Due to individual cultures and beliefs, there is no unified Native American response to disability but many tribes modeled the full inclusion of disabled workers in their societies. According to Arizona Community Health Representatives working with North American native populations, the Ojibwe culture was “broadly accepting” of people with physical disabilities and seizure disorders; among the Hopi and Mohican tribes, there was little stigmatization for disabilities such as epilepsy, diabetes, or hypertension (“Closing the distance,” 2010). In the Mohawk tribe, Kateri Tekakwitha, a woman who survived smallpox in the 1600’s, was left almost blind but performed the same work as her peers, participating in cooking, sewing, basket-weaving, and farming (Chauchetière, 1695/2007).

Among the North American Plains Tribes, a universal sign language was developed to assist tribesmen to effectively perform their main occupation of hunting. It was also very useful in battle (Mallery, 1881). Although this language had no origins connected to deafness or speech impairments, it inadvertently provided a means of inclusion for individuals with those disabilities and has been used by both deaf and hearing Native Americans for over 200 years (“Hand Talk: Preserving a language legacy,” 2010).

From the 17th to mid-19th centuries, the US economy was primarily farm-based, and many disabled people contributed to their family’s income. Depending on the nature and severity of the disability, individuals “were generally able to make a contribution, in varying degrees, to a largely rural production process” (Malhotra, 2001). In 19th century Canada, family members worked to the level of their capacities and

there were many tasks that someone with a mobility impairment or a learning disability could perform well. In this environment, an individual with disability was not necessarily considered a burden and there was no concept of such a person being “disabled” (Hanes, 2004). People with disability of the same era were productive on farms and in households in the United States, as well. Others worked in trades requiring precision handcrafting, making and repairing goods. Such employment allowed control of personal work schedules according to physical or psychological conditions (Russell, 2000).

Circumstances of daily life required teamwork to meet survival needs, causing community members to rely on each other to live. The practice of pooling talents despite inabilities and highlighting personal strengths to work together was not only common, but crucial. If capable individuals assumed leadership positions planning and directing tasks, it mattered little if someone had a learning disability or mental illness when brute strength was needed. If the willingness to contribute was present, such teamwork had great value. Consequently, the perception that, historically, all people with disability were burdens on their families and communities is inaccurate. In North America, disabled and non-disabled neighbors supported each other (Hanes, 2004).

This is not to say that people with disability did not experience difficulties and discrimination. Life was hard for poor people in general. Those unable to work had to rely on others and such assistance was not guaranteed. By the mid-1600’s, the American colonists established laws reflecting those in the English legal system determining “worthy” and “unworthy” poor status based on the ability and willingness to work. These laws were almost exact replicas of the Elizabethan Poor Laws (Trattner, 1994). Many who were considered societal problems were forced onto ships going back to Europe (Murray, 2003). In some places, disabled people were not welcomed to participate in community activi-

ties and some were disowned, hidden away or fatally neglected by family members (Fleischer, 2002). Despite this, many disabled people were productively employed.

Due to financial resources, children with disability born to affluent parents had enhanced career opportunities. Youngsters might be sent abroad for specialized training (Barnartt, 2001). Afforded the benefits of education, prosperous landowners, lawyers and merchants held positions of political, legal, and social importance. Since wealth and status were inherited, there was a vested interest in providing even heirs with poor health the opportunities to fulfill these roles (Brobeck, 1976).

If an individual had developed a trade before becoming disabled, depending on the nature or severity of the disability, s/he might possibly continue working at that job or at similar work because the necessary expertise was already developed. One example is the career of Edward Green, a railroad capitalist in Texas, who continued working years after his leg was amputated in 1887 (Cottrell, 2010). There were many officers, like Lieutenant General John Bell Hood, who, during the Civil War, continued his military career after being disabled and then upon discharge pursued other ventures (Hickman, 2010). Disabled people with prior work experience and familial or financial support systems had opportunities to be productive members of the workforce, fully assimilated into their communities.

On the southern plantations, enslaved workers were considered property with monetary value based on their ability to work. Consequently, many individuals, despite serious disabling conditions resulting from harsh treatment and lack of medical care, were assigned significant duties. For example, in Florida, after slaves became too disabled to work in cotton fields, they were shipped to New Orleans to work for the rest of their lives in the sugar houses (Weld, 1839). Many disabled slaves, barred

from the opportunity to leave plantations after emancipation, continued their work in gardens and households. Those individuals with disability, who did leave the plantations only to find themselves as patients in Freedmen Bureau's asylums, became the resident workforce performing tasks from "cultivating vegetable gardens to laundering clothes to building additional facilities" (Downs, 2008, para. 26).

## Industrial Revolution

As the United States economy became industry-based, masses of people left their farms and migrated to the cities for work. With large machines performing tasks that previously required the cooperation of many people, the need for teamwork and reliance on a group's combined abilities diminished. Workers were required to master specific, repetitive tasks within limited timeframes. Individual intelligence, strength, and talent became highly prized as the skillset required by employers. This effectively separated the "able" from the "unable"- soon to become classified "disabled" (Russell, 2000).

In a manufacturing environment based on a salary system, if one could not work, one could not survive. Unlike farm life, where, even in rough years, the land provided shelter and small communities cared for their own, city life rendered no such guarantees. In addition, factory environments were unhealthy and unsafe. Many workers, initially able-bodied and productive, were injured on the job. Without the unions and medical benefits of today, these individuals joined the ranks of "the disabled" by the hundreds. Thus originated and solidified the economic definition of disability as an "inability to work" (Barnartt, 2001, p. 5).

With a developing public education system that fostered obedience and uniformity to assure the compliance of a lower, working class (Gatto, 2003) and a growing interest in analyzing the political aspects of economics by categorizing "productive" and "unproductive" labor (Mill,

1885), it can be surmised that such concepts transferred to the definition of the traits of productive and unproductive workers. Almost overnight, these socially-created categories intentionally manipulated the workforce, allowing the capitalist elite to amalgamate wealth. Creating (and subsequently oppressing) the new group called “disabled” was foundational to corporate success (Russell, 2000). As this redesigned economic system thrived, unemployment increased and many people, with and without disability, had no means of support. Urban problems of overcrowding, slums, homelessness, begging, prostitution, and crime sprawled throughout US cities, disturbing the sensibilities of those in power. Seen as a major component of this troubling situation, disabled people now required management.

### **The Rise of Institutions**

As the number of people needing assistance grew, a harsh public view of the poor and disabled emerged and a “reluctant welfareism” evolved. Political and bureaucratic measures to manage the situation were devised utilizing the methods of segregation and institutionalization (Hanes, 2004). The creation of disability-specific institutions in the 19th century served many purposes, not the least being the isolation and “management” of disabled children and adults. This design, thought charitable at the time, had its roots in a caring paternalism that made decisions on “what was best” for people in need and society in general (Grizzard, 2004). Initially, many such facilities had inspired beginnings, the product of the labors of love of radical, free-thinkers of the day. These founders included vocational training programs to their curriculum. Manual training was an essential component of the coursework for deaf and/or blind boys and girls, with an emphasis on the rudiments of certain trades and the use of tools. In addition, the formation of habits of “industry” was as important as acquiring specific skillsets (Fay, 1893). Technical and mechanical arts were taught, resulting in many skilled occupations such as

cabinetry, shoe-making, knitting and sewing. Such education was indeed experimental and did not guarantee successful careers in the community. While there were facilities that asserted that their graduates were seldom unemployed, as today, some business owners were hesitant to hire them. Consequently, alumni might choose not to leave the institution at all, continuing on as employees and living in homes nearby (Barnartt, 2001). Even in institutions where residents were never expected to live and work out in the community because they were labeled “feeble-minded” (p. 105) or “mental defectives” (p. 103), farming, cooking, sewing, and maintenance skills were taught. Such duties were then performed in-house, effectively lowering facility labor costs (Trent, 1994).

Samuel Gridley Howe, a person deeply dedicated to assisting poor and disabled people, established the Perkins School for the Blind in 1832. In an address to the public, school administrators discussed potential employment opportunities as teachers, craftsman, clergyman, tailors/seamstresses, and musicians for educated blind students (Brooks, 1833). This belief that children with blindness were not pathetic invalids, doomed to a life of ignorance and begging, was extremely empowering at the time. Howe and his wife, Julia, also worked towards establishing special education and training for those with developmental disabilities and mental illness (Magner, 2000). Despite the growing belief that people with disability were incapable of industry and productivity, institutional programs in the US clearly demonstrated that with training and support, disabled individuals had marketable skills. By working effectively, they had the capacity to lead independent and productive lives without relying on charity.

During this time period, even if not affiliated with a specific institution, having the benefit of an education could lead to vocations as teachers and clergy. Religious ministries were instituted by disabled people for disabled people. For example, the Methodist Church has a long

tradition of a ministry for Deaf African Americans. Philip J. Hasenstab, the first black, deaf clergyman, began a mission in Chicago in 1894. He later collaborated with a fellow Deaf African American clergyman, Daniel Moylan, to found a similar interracial deaf mission in Baltimore. This historic enterprise later became known as The Christ Church, setting the example of racial integration in worship for the region ("Baltimore Deaf Church," 2004).

### **Freak Shows**

Although much current research has been conducted on the freak show phenomenon and many stories have now been told, a brief mention of their significance to this discussion is important. Despite present day distaste, in the 1800's, many of these shows provided viable employment for disabled people. For some, being onstage proved extremely lucrative. Two of the highest paid entertainers were the beautiful and musically talented conjoined twins, Violet and Daisy Hilton. It is reported that at their zenith in show business, they earned a combined salary of \$5000 per week ("Freaks of nature," 2000). Even today, such an income is noteworthy.

Ironically, though the performances reinforced racial and able-bodied superiority myths and set the entertainers apart from mainstream society, behind the scenes, belonging to the troupe was a venue for some participants to live fairly conventional lives. In the best scenarios, when the last curtain fell and the audience went home, the satisfied entertainers were left with each other - belonging, appreciated, each having a unique role in the show. Together they were not freaks, they were stars. In spite of abusive circumstances, children being sold by their parents for exhibition, and general mistreatment, there were performers who enjoyed happy marriages and family lives (Stanton, 1997). With all that can be said about the exploitation of people with disability, some individuals with little means of support and no chance of experiencing a sense of normalcy had a reason to

feel important as a freak show performer. By the 1950's, most shows had closed due to increased sensitivities to disabled people. But as "states began crackdowns...they were often opposed by the very people they were meant to protect" (Wolf, 2005). Even now freak show entertainers defend their careers. Performers claim that they live typical lives, working routine jobs and entertaining in the carnies on the side for added income. Popular shows like the one reincarnated at Coney Island and HBO's former television hit *Carnivale* indicate continued public interest; and Jennifer Miller's *Circus Amok* clearly demonstrates that performers are still willing and eager to earn money satisfying the public's continued fascination with freaks and geeks (Aponte-Gonzalez, 2006).

### **Employment Legislation for Veterans with Disability**

Beginning in the 1600's, North American colonists felt a responsibility to provide for the well-being of those soldiers who, upon returning home from active duty after being wounded in battles with Native Americans, would need assistance to secure housing, find and maintain employment and assimilate fully back into society.

As a result of the war with the Pequot Indians, the Pilgrims passed a law in the late 17th century that provided benefits to disabled veterans. In a rural environment where physical stamina and prowess could mean life or death, colonists knew that without supports, veterans and their families might not be able to survive. The root of legislation directly related to the employment of people with disability in the United States today lies in this civil act passed in 1693 (U.S. Department of Veterans Affairs, 2010).

After the Revolutionary War, veterans were granted pensions paid out of individual state funds by the Continental Congress of 1776. By 1789, the United States federal government began allocating resources for this purpose. Since

many wounded died, benefit rolls were relatively low until the Civil War. Due to improved hygiene and medical techniques, such as the prevalent practice of amputation, soldiers began sustaining injuries rather than succumbing to death (Adams, 2004). At the end of the Civil War, over 1.9 million veterans were added to the government rolls (U.S. Department of Veterans Affairs, 2011).

It was not until just before WWI that rehabilitation programs for US veterans were initiated, connecting employment needs with services for people with disability. “Among the provisions of the War Risk Insurance Act Amendments of 1917 was the authority to establish courses for rehabilitation and vocational training for veterans with dismemberment, sight, hearing, and other permanent disabilities” (U.S. Department of Veterans Affairs, n.d., pg. 7). Before that time, service provision was based on the paternalistic assumption that veterans, like all disabled people, were unable to take care of themselves; therefore benefit funds were spent on domiciliary, hospital, and medical care. This belief in the veterans’ dependent status was also reflected by the emphasis on providing family benefits. It was accepted that returning soldiers with disability were no longer able to support their families (Gross, 2005). The addition of vocational rehabilitation to government provisions for veterans not only positively affected the lives of WWI soldiers, but had far-reaching ramifications for other disabled United States citizens.

A series of laws addressing employment issues for veterans with disability established a federal-state vocational education program. Soon, this program was open to non-veterans. In 1920, the Smith-Fess Act (referred to as the Civilian Rehabilitation Act) began rehabilitation programs for all disabled US citizens (“A brief history,” n.d.). Only physical disabilities were covered; disablement being defined as a “physical defect or infirmity.” US federal vocational program services focused on those which would yield the best employment outcomes,

such as vocational guidance, counseling, education and training, occupational adjustment, and job placement services (Elliott, 2005).

Combined with the Social Security Act passed in 1935, such laws brought many disability issues to the forefront of US national affairs (Thompson, 1994). In addition, between WWI and WWII, there were numerous advances in medical procedures and medicines. The result was millions of veterans returned home in need of services after WWII. “In World War I, only about 2% of veterans with spinal-cord injuries survived more than a year, but three decades later during World War II, the discovery of antibiotics and more sophisticated medical interventions brought the survival rate up to 85%” (Welch, 1995).

These individuals were welcomed home by a grateful nation willing to provide them with education, housing, and vocational rehabilitation. Hardened and well organized warriors, these US veterans brought their energetic militancy into the arena of disability rights and their issues became prominent in the public eye. “Disabled soldiers were a difficult group to ignore” (Pompano, 2006). Veterans created support groups and foundations demanding assistance for individuals with physical and emotional disabilities.

In 1945, the Truman Administration, through the creation of the President’s Committee on Employment of People with Disabilities, directly encouraged employers to hire disabled people (Jennings, 2007). This move clearly and dramatically supported the veterans’ campaign. But these strides were not only a result of the hard work of the returned military; while soldiers were fighting far from home, civilians with disability began waging a war of their own.

## Employment Concerns in the Dawning Disability Rights Movement

In between the World Wars, during the Great Depression, the increasing popularity of the 20th century medical model resulted in narrowing the possible life experiences of people with disability, keeping the focus on what individuals could not do as a result of an impairment (Thompson, 1994). Times were financially challenging and disabled people wanted to work. If it was difficult for able-bodied workers to find jobs, it was next to impossible for those with disability. This caused anger and unrest.

In 1935, a militant New York City group of disabled people protested discrimination against workers with physical disability by the federal Works Progress Administration (Longmore, 2000). It was discovered that a job screening process eliminated all people with disability for work opportunities, regardless of their qualifications. When the news became public, instead of accepting the discriminatory practices, six people staged an immediate, impromptu sit-in. Soon, they were joined by other disabled demonstrators demanding jobs. The group eventually mobilized into the League of the Physically Handicapped. Their efforts resulted in over 1,500 jobs nationwide (Brown, 2000).

During the US Depression, protests were common, but militancy by people with disability was unprecedented. "Following the 1930's model of militant trade union protests," League members staged labor actions such as demonstrations, picket lines, and sit-ins in New York City and Washington, DC (Barnartt, 2001, p. 59). For the participants, more important than the jobs generated was the experience of emerging out of the closet of shame into the US mainstream. When interviewed years later, one woman said, "The protest transformed our view of ourselves" ("Scholar Uncovers," 1991). It was this new view that gave birth to the disability rights movement and fueled its progress towards

the goal of full inclusion in US society and into the world of work.

In the wake of the 1950's polio epidemic and as veterans assimilated back into society, national attention focused on civilian needs. Federal rehabilitation management was moved from the United States Veterans Administration to the new Department of Health, Education, and Welfare (Welch, 1995). There were more programs and support systems in place than ever before for disabled people who wanted to work, but many barriers remained. While there were laws in place to encourage employers to hire disabled candidates, there was no concurrent legislation addressing building or transportation accessibility. While a prospective employee might have all the qualifications for a position, acquiring and maintaining employment was not possible if s/he could not (1) arrive at the work location, (2) enter the building and while there, (3) use the restroom facilities. These issues would be addressed, although still not successfully remedied, in the decades ahead.

Many US civilians added their efforts to secure equal employment opportunities for disabled people. One person who was instrumental in bringing about positive change with employment initiatives was Henry Viscardi. Since childhood, Mr. Viscardi had artificial legs and used Canadian crutches. In 1944, while volunteering for the American Red Cross, it became apparent that he would be a wonderful coach to soldiers who had sustained amputations. Not only was he an expert on assistive devices, but his positive outlook and rich life experiences gave veterans hope for the future (Kiernan, 2004). In 1952, Viscardi started Abilities Inc. in Albertson, New York, a not-for-profit corporation that assisted disabled people to find jobs. Since then, as a result of his efforts, thousands of people with disability have secured work. In 2011, Abilities remains one of the world's foremost facilities for employment education, training and job placement (Abilities Inc., 2006).

## Conclusion

Currently, many employers in the United States perceive people with disability as “incapable” (Nelson, n.d.) and believe that a disabling condition renders someone unemployable (“Economics,” 2010). Without historical information about the careers of significant numbers of disabled people, it is hard to dispel such myths. But, people with disability can work, do work and have always been an active part of the United States workforce despite misperceptions and discrimination. Throughout US history, countless disabled individuals have participated in daily tribal work activities, hunted, farmed, labored in cottage industries, maintained careers in business, academic and legal professions, performed plantation operations, learned skilled trades in institutional settings, and supported themselves as entertainers. After military conflicts, disabled veterans returned to previous jobs or were re-trained to explore other careers.

Future investigations are needed to chronicle the even broader range of work experiences in the US after the 1950's and subsequent civil rights movements and employment-related legislations. Since many historical examples could not be included here, this paper serves as a preface to the body of work to come, providing a foundation upon which that future research can stand. Surely, this data will continue to demonstrate that, in many cases, being disabled does not have to result in being unemployed. In addition and of much more importance, it will reveal that the employment records of people with disability, though noteworthy, are neither astounding nor heroic—simply “business as usual.”

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# Deserving of Charity or Deserving of Better? The Continuing Legacy of the 1834 Poor Law Amendment Act for Britain's Deaf Population

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**Abstract:** This study will outline how deaf people in Britain were treated under the 1834 Poor Law Amendment Act and will argue that attitudes towards their abilities established by and in response to the New Poor Law continue to influence social policy provision and the employability of deaf people to this day.

**Key Words:** charity, deaf, voluntary welfare

## Introduction

As we reach the end of the first decade of the twenty-first century, it might be considered that employment opportunities for deaf people in the United Kingdom have never been greater. Laws protecting deaf people against discrimination in the provision of education, services and work would seem to help promote their employment prospects. However, statistics provided by two of the major UK welfare organisations for deaf people indicate that deaf people are still significantly disadvantaged in the workplace. These figures will be explored in more detail later in this study but two examples support the contention that deaf people are still un- and under-employed in comparison to their hearing contemporaries. In 2006, the Royal Institute for Deaf People (RNID) found that only 63% of British deaf people were in work, compared to 75% of the general population, whilst the Scottish Council on Deafness (SCoD) found that 70% of deaf people in Scotland felt that job applications had been unsuccessful because of their deafness (Royal National Institute for Deaf People, 2006; Scottish Council on Deafness, 2010). So why does the legislation not appear to be working?

One reason might be the nature of the laws enshrining deaf people's rights – all of which are linked to the notion of deafness as a disability. Funding introduced as a result of anti-discriminatory legislation, such as Disabled Students Allowance, Disability Working Allowance, and Access to Work all promote the rights of deaf people in terms of addressing disability issues. The various legislative measures only serve to highlight the apparent shortcomings of deaf people as effective workers, by emphasising the need for potential employers to adjust or amend working practices to accommodate deaf employees. The legal requirement to do so and the policies put in place to support and enforce these rights all serve to perpetuate popular perceptions of deaf people as incomplete and therefore worthy of preferential treatment in order to make them productive members of society. The precise impacts of such attitudes on deaf people's contemporary employment prospects, discussed later in this article, often clash with the political aspirations of deaf people themselves, especially sign language users (see, for example, Corker, 1998; Finkelstein, 1991; Ladd, 2003).

So how did these negative perceptions of deaf workers gain a hold in the popular understanding of deafness and find expression in British legislation and social policy? The contention of this study is that deaf people in Britain became the innocent victims of changes in manufacturing industry during the eighteenth and nineteenth centuries, and these changes gave rise to governmental responses to poverty and poor relief (Rose, 1972; Englander, 1998). In particular, it will be argued that the effects of the 1834 Poor Law Amendment Act not only continues to influence British social policy to-

wards poor and unemployed people but the effects of this legislation have determined the status of deaf people and affects their employment prospects to the present day.

The 1834 Poor Law Amendment Act was a watershed in institutionalising official attitudes towards poor and needy people in the United Kingdom, particularly in terms of establishing who was deemed worthy of support from state welfare provision. By extending existing notions of paupers as deserving or undeserving as the basis for receiving poor relief, and by running workhouses on the principle of “less eligibility,” the enduring political agenda for social welfare was established. This, in turn, influenced attitudes towards employability and acceptable unemployment amongst the deserving poor, who were seen as the innocent victims of physical and mental conditions that rendered them unsuitable for work and therefore worthy of state support (Rose, 1972). Consequently, a number of philanthropic organisations were established during the nineteenth century and many of these voluntary welfare bodies were established to offer an alternative to the workhouse (Shapely, 2000; Dimmock, 2001).

Although the Act and its provisions made no specific provision for deaf people, there were to be detrimental consequences for deaf paupers, particularly those legally categorised as “deaf and dumb.” Despite deafness of itself resulting in few – if any – physical restrictions on deaf people’s ability to work and maintain themselves, many deaf people were unemployed and so found themselves subjected to the rigors of the workhouse (Dimmock, 2001). This resulted in strenuous efforts being made to offer deaf people an alternative to state welfare based on voluntary charitable provision. However, whilst organisations such as the Association in Aid of the Deaf and Dumb (founded in 1841 as a direct consequence of deaf people being placed in workhouses) provided training, they did nothing to broaden outlooks on the types of work and trades at which deaf people could succeed.

## Poor Relief in England Prior to 1834

The duty of local authorities to care for the poor people in their area was first codified nationally under the rule of Elizabeth I, when Britain had a predominantly rural economy (Boyer, 1990). The 1601 Poor Law formalised a series of earlier measures into one coherent system, under which parishes were obliged to provide poor relief for paupers in their area through Poor Law Boards made up of local ratepayers (King, 2000). This Act brought in an important determining factor which underpins welfare provision in Britain to this day: the notion of there being deserving and undeserving poor. The distinction was a simple one: those who were unable to work through no fault of their own – for example the old, infirm, widows and children – were deserving, as were those who found themselves temporarily out of work due to the cyclical nature of the rural economy, with its peaks and troughs of employment needs (Lees, 1998). This latter grouping would be found work by the parish, in return for which they received support in the form of money, food, or fuel. On the other hand, those who were capable of working but chose not to do so were regarded as undeserving and were ineligible for support unless they too performed some form of work in return for poor relief (Englander, 1998).

Most support was given as outdoor relief, which allowed claimants to continue to live in their own homes; workhouses were also established but these were to be used only as a last resort. The poor law system thus established remained in place for over two hundred years, with various amendments and alterations being introduced at regular intervals (King, 2000). Two of the most important of these were enacted by Poor Law reformers Sir Edward Knatchbull in 1723 and Thomas Gilbert in 1782. Knatchbull’s Act introduced the first formal workhouse test and required claimants to reside in the workhouse, where they had to perform work in return for shelter and food (Rose, 1972). Having to enter the workhouse to receive relief be-

came a form of punishment for the undeserving poor, as the new rules imposed compulsory labour and residence in the workhouse on those unwilling to support themselves. Gilbert's Act of 1782 returned a more benevolent function to workhouses, by restricting admission to those deserving poor who were unable to look after themselves. All others were to be eligible only for outdoor relief, but both Acts did not compel the Poor Law Boards to follow these practices; they merely provided a framework for those who chose to adopt them (King, 2000).

During the late eighteenth and early nineteenth centuries, Britain moved from a predominantly agricultural economy to one that was increasingly industrialised and mechanised. One consequence of this shift was that the existing system of poor relief, which had developed to meet the needs of rural workers, proved inadequate to meet the demands of the rapidly expanding urban populations who serviced the new industries (Rose, 1972). The Poor Law in force at the time was seen to discourage the indolent poor from seeking work, and a series of trade depressions in the years around 1800 further increased pressure on the system (Lees, 1998). A major revision of poor relief was needed and this was introduced in 1834 through the Poor Law Amendment Act. Commonly known as "the New Poor Law," the 1834 Act introduced the principle of "less eligibility," which resulted in a much less flexible method of providing poor relief than had applied before. The term "less eligibility" is in many ways a misleading one, as it refers to the underlying philosophy of making workhouses the absolute last refuge of the most desperate poor. Rather than setting stricter rules on who was eligible to claim poor relief, in practical terms "less eligibility" meant dissuading as many people as possible from choosing to enter the workhouse. This was achieved in various ways: by providing support at a level that was less than could be obtained by taking the lowest paid, locally available work; by making claimants reside in the workhouse; and by ensuring that life in the workhouse was unpleasant and

undesirable. Couples were separated and often only met for a brief period each Sunday, and all aspects of life in the workhouse were strictly regulated. Inmates were expected to provide various services which produced an income to pay for the assistance they received. These were often tedious and repetitive jobs such as washing and dyeing old clothes for inmates to wear and picking apart old ropes to provide the raw materials to make new ones. Children were often hired out to local factories and their meager wages paid to the workhouse overseers. In effect, all but the most incapacitated of workhouse inmates had to earn their keep. All this was meant to ensure that only those who were genuinely unable to support themselves or their families would claim poor relief and so reduce the burden on those who had to fund the system of poor relief (Englander, 1998).

As they had been under Knatchbull's Act, workhouses once again acted as a deterrent for the undeserving poor, whose status was determined by whether they were regarded as impotent or able-bodied. The impotent poor fell into one of five categories: children, the sick, the insane, defectives, and the aged and infirm (Wright, 2000). Michael Oliver (1990) contends that anyone who did not come under one or more of these headings was consequently classified as able-bodied; however Michael Rose (1972) has suggested that in practice all adult paupers between the ages of 16 and 70 were automatically regarded as able-bodied unless they were permanently incapacitated in some way. So, entering the workhouse was generally the only form of support available to paupers, where all were subjected to the same strict regime. Husbands and wives often found themselves living in different parts of the workhouses, only meeting for brief periods on Sundays. Those who were deemed able to work had to perform various tasks in return for their upkeep, with a typical ten hour working day beginning at 5.00 am and ending with bed at 8.00 pm. Whilst food was provided, this was at little more than subsistence level (Gash, 1973). Thus the pun-

ishment of the indolent poor was extended to all those unfortunate enough to have no other option than the workhouse.

### **The Consequences of the 1834 Poor Law Amendment Act for Deaf People**

Where did this change in the law leave deaf people? Records such as the ten yearly census returns (introduced in 1841) and the 1861 National Index of Paupers indicate they could find themselves forced into the workhouses after 1834 (The UK & Ireland Genealogical Information Service, 1997). Whether they were admitted as deserving or undeserving poor is unclear and remains open to some debate. On the one hand, their deafness (particularly for those officially classified as “deaf and dumb”), coupled with historical perceptions of deafness as a handicap or impairment (Grant, 1990), suggests they might have been regarded as impotent and therefore deserving. However, in practical terms, deafness would appear to present no barrier to performing any number of useful and productive jobs, so a more equal – but ultimately harsher – interpretation might have seen them classed as indolent and therefore undeserving. Given that indolence was seen to arise from a moral defect rather than a physical condition (King, 2000), it is more likely that deaf people were accepted into workhouses as deserving poor, with their deafness classifying them as impotent in employment terms. Either way, this was seen as a situation that needed to be addressed and a number of voluntary welfare bodies emerged in the aftermath of the New Poor Law to provide deaf people with a means to avoid entering the workhouses (Dimmock, 2001). It is perhaps no coincidence that these local organisations (the first of which appeared in Scotland around 1820) grew in number after 1834 (Lysons, 1991).

The first large scale welfare body for deaf people was established with the declared purpose of rescuing deaf people out of the workhouses by providing skills and trades through

which they could find work and support themselves (Dimmock, 2001). The Institution for Providing Employment, Relief, and Religious Instruction for the Deaf and Dumb was founded in London in 1841, later changing its title to The Royal Association in Aid of Deaf People (RAD). Formed as a charitable organisation, the RAD set up missions across south-east England to provide training in various trades such as printing, bookbinding, and shoemaking for men, followed later by dressmaking and needlework for women. Two important factors in the RAD’s work were to influence both voluntary support for deaf people and government attitudes towards deaf people’s employability and social policy provision (Dimmock, 2001).

Firstly, the RAD was allowed to register as a charity, thus explicitly and implicitly identifying deaf people as the worthy recipients of charitable donations and all that entails in terms of public perceptions. Secondly, Missioners were introduced to provide care and welfare for the deaf people in their area, which included finding work and apprenticeships for deaf people. They also acted as advocates and advisors to deaf people in their areas, as well as providing interpreting between sign language and spoken language for deaf and hearing people (Dimmock, 2001). This role, which was adopted in various forms by all subsequent deaf welfare bodies, established the view that deaf people were unable to deal with various aspects of daily life, such as finding employment, and needed the help of the hearing world. This perspective was based solely on a perception of deafness as a loss or a deficit, which renders deaf people in some way incomplete and therefore unable to function “normally” whether in their working, family or social lives (Finkelstein, 1991).

As a result, deaf people became participants in the process by which they became institutionalised as needing care on the one hand and being worthy of such care on the other. Even the emergence of the British Deaf and Dumb Association in 1890 as the first national organisation

of deaf people (now the British Deaf Association – BDA) unwittingly helped to support this vision of deaf people and their perceived lack of abilities (Grant, 1990). The BDA adopted many of the roles and practices of the RAD, including Missioners who acted on behalf of deaf people in finding jobs and accessing services. Although the BDA played a vital role in providing practical help for deaf people, their work was confined within the deaf world and so the image of deaf people being unable to cope with daily life was not challenged in the public domain. Many deaf people preferred to rely on their Missioners to find them work and provide welfare support (Grant, 1990). Consequently, both the deaf organisations and the people they serve have helped (even if subconsciously) to perpetuate the notion that deafness is sufficient reason to regard someone as deserving of charity, as defined in Poor Law legislation dating back to 1601.

### **The Continuing Effects for Deaf People**

In the early years of the twenty-first century, the legislation that protects deaf people's rights in all aspects of life explicitly describes deafness in terms of disability. The 1995 Disability Discrimination Act helped codify disabled people's rights in employment and access to services, with deafness included in the Act's definition of disability (DirectGov, 2010). Deaf people are also eligible to apply for Disabled Living Allowance and Disabled Working Allowance (both introduced in 1992), whilst the costs of providing equipment such as text phones and human support (interpreters, note takers, etc.) to allow deaf people to work alongside hearing colleagues is provided through the Access to Work (ATW) scheme. ATW funding is explicitly intended to support disabled people in the workplace, through the provision of any technological or human assistance that may be required (DirectGov, 2010a). The Equality Acts of 2006 and 2010 further strengthen the rights

of disabled people in all areas of life and again include employment and service provision for deaf people (DirectGov, 2010b). Equality legislation implies inequality as its starting point and seeks to address these differences in a positive and affirmative way. Indeed, it is now mandatory for all disabled people to be assessed on their ability to work, rather than their inabilities (Woolfe, 2004).

However, this legislation also emphasises to potential employers the ways in which their business practices may need to change if they employ deaf people. Companies can no longer discriminate against deaf workers if "reasonable adjustments" to working conditions can be made, such as providing alternative technology and human support in the workplace (DirectGov, 2010). Recent changes to Access to Work funding are unfortunately timed, as these now place a greater financial responsibility on employers to fund disabled workers when many businesses are under severe financial stress (DirectGov, 2010a). These changes, which will see employers having to pay up to £1,000 annually towards the costs of supporting a disabled person in the workplace (using such services as note takers and sign language interpreters for meetings and training events), are likely to make deaf employees appear more costly to employ than their hearing colleagues.

Despite all the legal protections for deaf people in the workplace and the range of funding and support available, two recent surveys demonstrated that deaf people are more likely to be unemployed and underemployed than their hearing counterparts. In May 2006, the Royal National Institute for Deaf People (RNID) found that 37% of deaf people of working age were unemployed, compared to 25% of the hearing population (Royal National Institute for Deaf People, 2006). Similar research by the Scottish Council on Deafness (SCoD) found that deaf people were four times more likely to be unemployed than non-disabled people (Scottish Council on Deafness, 2010). Of those deaf

people in work, frustration and a lack of fulfillment in their lives appear to be constant factors. Over half of RNID's contributors felt "they had been held back from promotion or developing their career" whilst three-quarters of the Scottish respondents claimed they were prevented from progressing at work because of their deafness (Royal National Institute for Deaf People, 2006). A third of the RNID sample felt under-employed, as their job failed to make full use of their qualifications, whilst in Scotland over half thought they had "been prevented from pursuing further training or education because of their deafness or lack of communication services" (Scottish Council on Deafness, 2010). Relationships with hearing colleagues also left many respondents feeling unfulfilled and unrewarded, with over 50% of SCoD interviewees unable to communicate with hearing co-workers, whilst the RNID found 75% felt deaf awareness training would improve their working lives. 26% reported they had been harassed at work because of their deafness, despite such action being explicitly addressed by both disability and employment legislation (Royal National Institute for Deaf People, 2006; Scottish Council on Deafness, 2010).

The RNID survey found deaf people working at all levels in a wide variety of jobs and careers, but for sign language users the options are much more restricted, due mostly to communication barriers (Royal National Institute for Deaf People, 2006). Issues of isolation and lack of opportunity are even more acute for sign language users, for whom access issues and convincing employers of their suitability for a range of jobs involving contact with the general public remain problematic. The lack of deaf people in many areas of work suggests that deaf people are being denied employment opportunities because of what their deafness represents to employers, rather than any inherent lack of skill or ability (Royal National Institute for Deaf People, 2006).

When deaf people do find rewarding employment, Tyron Woolfe (2004) suggests that these opportunities too often arise within a narrow range of jobs and that deaf people themselves are helping to support the notion that they are only capable of doing certain kinds of work. Woolfe argues that many deaf people follow one of three employment options in the United Kingdom: working for deaf organisations, running their own businesses, or on long term social security benefits. He points out that even amongst deaf professionals there is an expectation (both amongst deaf people and from outside) that they will work in deaf fields. Thus, deaf teachers will almost always teach deaf children, deaf counselors will largely work with deaf people, and those with media qualifications will work on deaf-related publications and programmes (Woolfe, 2004).

A similar pattern emerges amongst those deaf people who set up their own businesses (as many as 8% of the RNID survey were self-employed), with Woolfe (2004) claiming they tend to concentrate on providing services solely to other deaf people. By effectively isolating themselves from mainstream work and society, those deaf people who only work with other deaf people help to continue perceptions of deaf people needing to be helped and cared for by others, even when those "others" are themselves deaf. Far from being empowering, deaf people are effectively isolating themselves from mainstream work and society, rather than being fully integrated and accepted as equals. For the third group, the long term benefits claimants, it is here that the consequences of the 1834 Poor Law are most obviously maintained. Assessment of a disabled person's ability to work only occurs at age 18, whilst benefits can be claimed from age 16 (Woolfe, 2004). By 18, institutional perceptions of deaf people's employment prospects, coupled with a lack of positive role models, make staying on benefits more attractive than taking a low paid, low status job.

## Conclusion

When the Poor Law Amendment Act was introduced over 175 years ago, it was a response to the demands of a changing industrial and economic environment and was not intended to deal with the particular needs of deaf people. Nevertheless, the unintended and almost certainly unforeseen effects of that legislation are still being felt by deaf people today. Legislation aimed at improving job and career prospects for deaf people is predicated on the perceptions and notions inherent in the New Poor Law and the actions of various philanthropic bodies in response to the change in poor relief law. Despite the benefits that have accrued for deaf people in recent years, there is still a long way to go before deaf people achieve parity with hearing people in terms of un- and under-employment.

All graduates from UK universities face a difficult job market; the increasing numbers of deaf and signing graduates are finding that taking and gaining a degree only delays problems in finding skilled work and rewarding jobs outside the narrow parameters outlined by Wolfe (2004). The 1834 Poor Law Amendment Act established the idea that deafness, of itself, is sufficient to warrant special – and even charitable – consideration. It is the contention of this paper that the 1834 Act has ultimately helped to establish two underlying principles of social policy which have not served deaf people well in employment terms: “It’s not their fault they are deaf” and the subtly different but no less influential: “It’s not their fault. They are deaf.” The reality of working life for many deaf people in Britain, as demonstrated by the surveys conducted by the Royal National Institute for Deaf People (2006) and the Scottish Council on Deafness (2010), is that deaf people will at best work in a financially and emotionally unrewarding job, with little or no social contact with their hearing colleagues. This is then likely to be compounded by little prospect of promotion or realistic opportunities for positive career choices. For unemployed deaf people, the prospects

are even bleaker, with a life on social security benefits making more financial sense than taking an unskilled, low paid job. All deaf people in the UK now have rights under employment law and benefits legislation that are intended to end discrimination but these are predicated on notions of deafness as a disability. As a result, the changes to the Poor Law that occurred two centuries earlier continue to influence portrayals of deaf people as being worthy of charity rather than useful and productive members of society.

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# “Useless”: Disability, Slave Labor, and Contradiction on Antebellum Southern Plantations

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## FORUM

**Abstract:** African American slaves with disabilities (broadly defined as physical, mental or aesthetic conditions seen as unfavorable or impairing) performed a variety of duties on antebellum southern plantations. However, tensions between goals of production, profit, control, and planters’ expectations often created contradictory assessments of disability in slaves. Slaves with disabilities were also at risk of abuse—including corporeal punishment, neglect, and murder—from masters.

**Key Words:** African-American history, slavery, plantation labor

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### Introduction

In the mid-1830s, Samuel G. Barker, a Charleston attorney and slaveholder, composed a detailed list of 87 plantation slaves in his estate book. The list identified Barker’s bondspeople<sup>1</sup> by their names, dates of birth, and gender, but also included descriptions of skills and identifying characteristics, accorded each person a “hand” rating, and noted whether they were considered “diseased” or “useless.” Among the slaves identified as “useless” were Old Stephen, who “rakes trash;” Old Betty, a nurse and midwife; Peggy, who “cooks for negroes;” Bess, a 23-year-old “feeble” woman who “can cook;” and Old Minda, a “first rate midwife and nurse” (Barker, n.d.). Other plantation records also categorized slaves as “useless” alongside descriptions of the duties those slaves performed. For example, in a chart from Edmund Ravenel’s Grove plantation in South Carolina, a column of “useless” female slaves included a cook named Mary, a nurse named Cotto, and Sary, a blind woman

who minded poultry (Untitled List of Slaves, 1825). The contradiction between “uselessness” and utility embedded in these impersonal charts raise important questions about the roles of slaves with disabilities—defined here broadly as a number of physical, mental or aesthetic conditions that were viewed as unfavorable or impairing—on southern plantations, how slaveholders assessed the worth and utility of those slaves, and what kinds of treatment “useless” laborers received at the hands of masters and overseers.

Barker’s and Ravenel’s seemingly unproblematic use of the word “useless” to classify slaves with disabilities, even as they described the uses to which those slaves were assigned on their plantations, indicates the planters had clear ideas of what the term meant to them, but there were many different reasons a slave might be considered “useless” in antebellum society. In his 1839 compendium *American Slavery As It Is*, abolitionist Theodore Dwight Weld indicates that slaveholders used the term “unprofitable” to describe disabled human chattel (pp. 132-33). However, “useless” could also denote a failure to live up to expected duties for a particular social role; in the case of slaves, this might be their ability to perform manual labor, to reproduce and add to a master’s labor force, or to be disciplined and controlled (Hackford, 2004). On a more personal level, slaveholders could have used the term to describe a slave who did not meet a master’s individual expectations for behavior, physical appearance, and performance. Tensions between goals of profit, production, control, and the individual desires of planters created a number of contradictions in the ways planters assessed disability and “uselessness” in their laborers.

## Background: Plantation Labor Systems in the Antebellum South

In order to discuss the roles of “useless” slaves on southern plantations, it is necessary to describe the operation and types of work performed in complex plantation labor systems in the early nineteenth century. Although the number of white “planter aristocrats” was small, the majority of African American slaves lived at least part of their lives on large plantations and participated in plantation labor systems. The term “planter” did not have a single meaning in the antebellum South—in some cases, it was synonymous with “farmer” and did not indicate the number of slaves owned—but by the early nineteenth century, when the majority of farmland in the eastern South was cultivated and most larger estates had been established, the term usually referred to slaveholders with large, or multiple, estates, and at least twenty slaves. As Oakes (1998) has noted, the large plantation ideal—a profitable, efficient model of mastery and production—influenced many slaveholders’ identities and organization of labor systems. Most planters in the antebellum South planned labor schemes based on a “hand” system, a measure of proportional function that could be used to rank different slaves within any specific job category. In general, a person who was able to perform the expected amount of a full day’s labor for an adult, able-bodied male slave was assessed to be a “full” hand. Full hands did the bulk of hard field labor, while three-quarter, half and quarter hands—including “elderly” slaves over the age of fifty or sixty, pregnant women or individuals with physical or mental impairments—were assigned less strenuous tasks (Bankole, 1998; Davis, 2006; Joyner, 1984). The overriding principle of plantation management was the discipline of the enslaved labor force, which was managed hierarchically by white overseers and white or black drivers (Oakes, 1998). House slaves may have been rated “full” hands, or “prime” in market terms, but domestic tasks were generally less strenuous and involved more

direct supervision from white masters, as well as less interaction with other slaves.

Although many planters strove for efficiency and maximum output in their labor scheme designs (Genovese, 1974; Oakes, 1998), slave populations were constantly in flux, and the structure of labor had to be fluid to accommodate these changes. Since a slave was expected to work for his or her entire lifetime, a slave’s “hand” rating and place in the plantation labor system were subject to change, and many slaves were, at some point, evaluated as less than a “full” hand. For instance, Maryland ex-slave Charles Ball (1859), describing his experiences on a large South Carolina plantation in the early nineteenth century, noted that of 263 slaves in that community, only 170 were “full hand” field workers; “the others were children, too small to be of any service as laborers...old and blind persons, or incurably diseased.” Of those, “the most handsome and sprightly” were chosen to serve as house servants for the white slaveholding family, while the others performed a variety of non-field tasks (p. 117). Such a labor scheme was not uncommon in the antebellum South, since slaveholders considered their human chattel to be lifetime investments, and placed them to work for as many years as possible. However, plantation labor schemes were not under the absolute control of slaveholders and overseers; slaves themselves, by setting their own work rhythms and demonstrating the range of their abilities, were in a position to negotiate the amount and type of labor they would perform (Davis, 2006; Genovese, 1974).

Plantation records—letters, journals, memoirs, and inventories of slave work gangs—are useful primary sources to demonstrate the wide range of duties that slaves of different ages and abilities performed. In many cases, disabled slaves were employed in a variety of tasks that did not involve field labor. Some slaveholders assigned trusted elderly male slaves to be drivers for field laborers, positions that rewarded faithful bondsmen and capitalized on the slave com-

munity's respect for its older members (Jones, 1990; Pollard, 1996). For instance, Paul, a "very trusty" driver on Samuel G. Barker's plantation, was categorized as a full hand despite his being older and "diseased" from a hernia, or "rupture" (Barker, n.d.). Elderly or disabled slaves regardless of gender also worked in plantation kitchens and watched children. A journal from the medium-sized Rockingham Plantation in Brunson, South Carolina included a list of "not all taskable" slaves on the plantation in 1828 and 1829, including a driver, a "Nurs" [sic], a gardener, dairy workers, stock and poultry minders" (Rockingham Plantation Journal, 1828-1829, Sec. A, p. 1). Indeed, the wide variety of duties necessary for the successful management of large plantations ensured that there were a number of different jobs for slaves with disabilities.

Some planters felt that such specific, "simple" jobs were particularly suited to bondspople with physical or mental impairments (Postell, 1953). As Louisiana planter Haller Nutt complained in an 1843 journal entry, overseers sometimes erroneously assigned "hearty strong negros [sic]" to simple tasks "which could be done equally as well by some feeble hand or cripple" (Nutt, [1843-1850], p. 5). However, the simple jobs that disabled slaves often performed were not necessarily easy; for instance, New Hampshire native Emily Burke's memoir (1991) of life in Georgia in the 1840s claims that "the task of the cook was the most laborious" of all house servant positions, since cooks had to rise early, prepare lots of meals, and perform strenuous tasks like grinding meal or meat and gathering firewood (p. 41). Burke also notes that some elderly women held the job of watching over plantation nurseries—which could include children from one week to five years old—and "it is no small task for two or three of these females, themselves in a second infancy, to rock the cradles and attend to the wants of twenty or thirty young children" (p. 91). Furthermore, old age or physical impairment did not automatically preclude a slave from being assigned to hard labor. On the Ball family's Limerick plantation

in South Carolina, an 1807 crew assigned "to work on the roads" included several "old hands past muster" like Old Billy, Old Handy, and Old July (Ball Family, 1807). For some slaves with disabling conditions, learning a skilled trade seemed like a better alternative than field or house labor. In a letter from slave Nancy Venture Woods to her master in 1825, Woods asks that her grandson Virgin be trained as a tailor or shoemaker, because he was impaired by "a hurt he has had in his ancle [sic] which he still feels at times" (Starobin, 1974, p. 87). James L. Smith (1881), a slave who had become disabled in childhood, was trained in shoemaking, and placed to work in a shop in Heathsville, Virginia. These examples indicate that slaves with perceived disabilities were employed in a wide variety of duties—and not necessarily easy ones—in and out of plantation labor systems in the antebellum South.

The overseer's journals for planter George Kollock's Ossabaw Island plantation allow us to trace the career of one disabled slave, a blind man named March, to demonstrate the utility of disabled slaves. Around 1850, as Kollock was consolidating assets on a new plantation, March was rated to be a "quarter hand," with no indication of the jobs he was expected to perform at that time. In the 1850 and 1851 journals March is not included in tallies of cotton pickings by weight, unlike most other male slaves on the plantation, and is never mentioned by name in daily work logs or sick lists (Kollock, 1850). However, the 1855 journal notes that March had two sick days, one in January and one in July, indicating at that time he performed some sort of work for which an absence was noteworthy (Kollock, 1855). In 1858, March was listed as one of the "hands that went to bring back [the] boat" that had carried a few slaves "to town" for Christmas (Kollock, 1858, p. 2), and in early 1859, overseer H. Jarrel composed a letter to Kollock, indicating that March wanted his master to measure bushels of corn he had shelled (Kollock, 1859). This evidence of March's work at Ossabaw Island, though fragmentary, offers

a glimpse at the role of a disabled slave on a growing cotton plantation. In 1850, when the plantation was young and the labor system not fully realized, a slave like March, whose blindness may have prevented him from performing the labor necessary to establish plantation fields, would seem relatively unimportant to his master and overseers. However, after several years it seems that March had been assigned to tasks that were important to the running of the established plantation; his illness merited a notation in the journal because the overseer viewed it as “time lost.” Most importantly, the fact that March made an appeal through the overseer, to his master to view the corn he had shelled indicates he had been assigned to a regular task, and might suggest that his performance had accorded him a degree of respect from white authority figures. The experiences of March on Kollock’s Ossabaw Island plantation are a good indication of the different kinds of work slaves with disabilities performed, as well as the fluidity of plantation labor systems.

### **The Devaluation of Slaves with Disabilities**

As these sources indicate, the successful management of a large plantation involved a variety of different tasks, some of which were performed routinely by slaves who were considered disabled. However, despite the different kinds of important work that elderly or impaired plantation slaves performed, slaveholders often explicitly or implicitly devalued such slaves. Although Postell (1953) claimed that “unsound” slaves were often appraised at or near market rates in estate inventories (p. 52), Fett (2002) has argued that appraisals of elderly and impaired slaves, despite their skills or labor histories, were usually very low. For example, slaves belonging to Charles Carroll, a Chesapeake Bay planter and the last surviving signer of the Declaration of Independence, were appraised in the early 1830s; nineteen of his slaves were described as extremely old, crip-

pled or diseased, and valued at one penny apiece (Franklin & Schweining, 1999). In 1854, the estate of Bennet H. Barrow included a 43-year-old blind slave named Temps (or Demps) who was appraised at fifty dollars, the same price as infants; other male slaves in their forties were valued between seven and nine hundred-fifty dollars (Davis, 1943). This evidence indicates that slaveholders who considered their disabled slaves “useless” were concerned with their resale values, rather than the labor they were actually capable of performing.

The economic devaluation of slaves with disabilities seems to have been a common, unremarkable practice, but the handling of plantation slaves with disabilities was a sensitive subject in the antebellum United States. This was particularly apparent in discussions of the treatment of slaves impaired by old age, who had resided on plantations for their entire lives but were unable to continue in the jobs they had performed when they were younger. Although some planters manumitted elderly slaves who could no longer work, most elderly slaves remained on plantations with their families, and their masters were expected to provide for them until they died. Many proslavery advocates highlighted the care and affection shown to older slaves as an indication of the institution’s overall benevolence, but in many antislavery accounts, elderly and disabled were more frequently subjected to abuse than kind treatment at the hands of their masters. Disabled slaves could be punished for their limitations, or inability to perform certain tasks or work as effectively as others; slaves with physical or mental limitations often worked more slowly and had trouble with the physical demands of plantation labor, affirming a common stereotype that African Americans were inherently “lazy” (Genovese, 1974, p. 298). Philemon Bliss, an Ohio minister who had lived near Tallahassee, Florida, in the mid-1830s, noted that “the most common cause of punishments [for slaves] is not finishing tasks” (Weld, 1839, p. 103). Old age or disability did not stay the whips of slavehold-

ers; Frederick Douglass (1845/1986) recalled watching one of his former masters, Colonel Lloyd, “make old Barney, a man between fifty and sixty years of age, uncover his bald head, kneel down upon the cold, damp ground, and receive upon his naked and toil-worn shoulders more than thirty lashes at a time” for unsatisfactory performance (p. 61).

There are many other examples of slaves who faced neglect when age or disability prevented them from working (Genovese, 1974; Pollard, 1996). Less profitable slaves often received reduced rations from masters; ex-slave Harriet Jacobs (1861/2000) recalled an elderly, “faithful” servant whose mistress denied him an allowance of meat, claiming “that when niggers were too old to work, they ought to be fed on grass” (p. 104). Some slaveholders sold their worn out slaves to remove the burden of caring for disabled property (Craft, 1860). In 1852 escaped slave Henry Bibb composed a series of letters to his former master, Albert G. Sibley, chastising him for selling Bibb’s aging mother after promising her liberty. Bibb’s mother was forced to work for six years as the chief cook in a Bedford, Kentucky hotel, which left “her constitution... completely broken” and rendered her unable to care for herself (Blassingame, 1977, pp. 54-55). Others manumitted their elderly and disabled chattel and sent them to southern cities, abandoning them to a life with no financial or community support. Burke (1991) described an asylum in Savannah, where “old and worn out” slaves “left without any sort of home or means of subsistence” often ended up; in Burke’s estimation, life in the dreaded institution was “next to having no home at all, and those who avail themselves of the comforts it affords only do it when every other resource for the means of subsistence fails them” (pp. 24-25). Increasingly strict legislation against manumission in the later antebellum years largely precluded this practice, protecting elderly or infirm slaves while also preventing them from becoming public charges (Genovese, 1960, 1974; White, 1999). There were, however, slaveholders who

bent these laws; Louisiana planter Bennet H. Barrow noted in his diary in 1842 that “Uncle Bat. told my boy to turn old Demps loose & let him go. Been runaway for some months...he shall not stay in this neighbourhood [sic].” Apparently, Demps, an “old & cripple” man, had been treated badly by his owner (Davis, 1943, p. 262), and probably welcomed the chance to flee; from his master’s perspective, however, allowing Demps to escape was an expedient method for Barrow to free himself from the burden of caring for a disabled slave.

More commonly, slaveholders abandoned elderly and disabled bondspeople without sending them away from the plantation. When the “usefulness” of slaves ran out, particularly due to old age or blindness, they were often sent to rooms or cabins in the woods to live alone and fend for themselves, separated from masters and the slave community (Owens, 1976). In 1813, Mary Woodson wrote to the mayor of Alexandria, Virginia, to relate the story of a disabled slave who was left by her master to live alone. According to Woodson, the slave, “the property of on[e] Posten in whose service she was burnt almost to death before Easter,” had been isolated in a single room “without a change of clothing, or one single necessary of life, or comfort” (Owens, 1976, p. 48). Similarly, abolitionist Philo Tower (1856) described meeting a superannuated and blind woman whose master had consigned her to live alone in a shanty, and gave her no provisions except corn. The woman told Tower that she did not have adequate clothing, and “suffer[ed] a good deal from cold in the winter”; she also had no one to bring her water, and was too feeble to carry it herself. Her twelve children had all been sold—at a profit of at least six thousand dollars, according to Tower’s estimate—and the lonely woman, who had spent seventy years laboring in the cotton field, essentially waited to die (pp. 170-72).

In a few extreme cases, elderly and disabled slaves were murdered for their inability to perform satisfactory labor. Northern journalist

James Redpath (1859/1968) recalled a conversation with an elderly male slave who had witnessed the homicide of an ailing girl. Her overseer was frustrated that the girl was “lagging behind” and ordered her “to mend her gait”; when the girl replied that she was “so sick I kin hardly drag one foot after the other,” he struck her on the neck. The girl “was taken up insensible, and lingered till the following morning” (p. 120). On Haller Nutt’s Araby Plantation in 1843, the planter reported several slave deaths that resulted “from cruelty of overseer,” including that of a man who was “beat to death when too sick to work” (Nutt, [1843-1850], p. 205). Although slave murder was technically illegal, there are cases of slaveholders who escaped responsibility for killing their disabled slaves. Burke (1991) recalled the story of an “old feeble woman” who was sold to a new master, and made to work in the fields for the first time in her life. After sustaining a severe beating, “she was scarcely able to supper her weight upon her feet” and could not wield her hoe to the satisfaction of her master; he “gave her a blow to the neck, and she fell dead at his feet.” Several days later, physicians performed a postmortem examination and determined that the slave had been murdered, but her master had left the plantation and could not be found. Eventually, “the excitement died away, and as it was only a poor old slave when the cruel tyrant did return the whole matter was nearly forgotten” (pp. 59-60). Similarly, in his personal journal, Sea Islands planter Thomas B. Chaplin described the murder of Roger, a disabled slave who had belonged to neighboring planter James H. Sandiford, in February 1849. Apparently, Roger had been late in returning with oysters, and received a beating from Sandiford; later, Roger was overheard telling another slave “that if he had sound limbs, he would not take a flogging from any white man,” which his master interpreted as insubordination. Sandiford then shackled Roger in wet clothing in an open outhouse overnight, where he died not from exposure, but from strangulation from the chain around his neck after Roger “slipped from

the position in which he was placed.” Roger’s death was deemed to be accidental, but Chaplin felt “the verdict should have been that Roger came to his death by inhumane treatment to him by his master” (Rosengarten, 1986, pp. 456-67).

All of these examples, which appeared in published abolitionist propaganda as well as private plantation records, indicate there was certainly a broad spectrum of the treatment of slaves with disabilities. However, although elderly and disabled slaves’ experiences ranged from kind treatment to being ignored or mistreated, it seems that planters were often indifferent, if not overtly hostile, to “useless” slaves who were unable to do the work their masters expected or desired, although those slaves were often assigned to necessary duties. Such examples indicate that the existence of disabilities in slaves, including impairments due to old age after a lifetime of service, played a significant role in masters’ treatment of their disabled human chattel.

## Conclusion

In developed antebellum plantation labor systems, there were a number of jobs and skill levels required of slaves, and even those with perceived disabilities were used for different kinds of labor. The fact that planters like Samuel Barker and Edmund Ravenel would categorize some of their slaves as “useless” even as they described the duties that “useless” slaves performed illuminates a fascinating and underexplored contradiction in assessments of disabled bondpeople. Based on evidence in plantation work logs, correspondence and estate inventories as well as published sources, it is clear that, although individuals with disabilities could do a number of jobs that were necessary to the running of plantations, many slaveholders devalued their disabled slaves, and subjected them to a number of abuses—including punishment, neglect, and even murder—because of their disabilities. The contradiction of using

the “useless” on antebellum plantations calls into question the assumption that planters only ascribed to economic motivations in their assessments of their bondpeople. As this article suggests, a variety of other factors—including issues of control and discipline, and psychological or emotional reactions to impaired enslaved bodies—were involved in how planters assessed the utility and performance of slaves with disabilities. The careers of “useless” plantation slaves and their treatment at the hands of masters, therefore, provide an important glimpse at different, and sometimes contradictory, factors that contributed to ideas of slave disability and labor in the antebellum United States.

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## Endnotes

<sup>1</sup> For the sake of variety, I use the terms “slave” and “bondsperson” interchangeably throughout the paper.

# Electioneering and Activism at the Turn of the Century and the Politics of Disablement: The Legacy of E.T. Kingsley (1856-1929)

This article is dedicated to the memories of Ross and Olive Skene Johnson. You were certainly right to try.

**Ravi A. Malhotra, University of Ottawa, Ontario Canada**

## FORUM

**Abstract:** The lost career of Eugene T. Kingsley (1856-1929), an American-Canadian socialist who ran for the House of Representatives, the Canadian House of Commons and the British Columbia Legislature, has much to teach disability studies scholars. A double amputee who walked with a cane and artificial limbs, Kingsley was radicalized after an industrial accident in California and went on to become a central leader of the Socialist Party of Canada. In this article, I document his career and reflect on his legacy.

**Key Words:** socialism, amputee, Canada.

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

People with mobility impairments have typically been regarded as non-participants in the capitalist labour market and objects of pity by scholars of all ideological hues (Stone, 1984). Yet many people with mobility impairments have made important contributions in a variety of roles and capacities throughout history, even if they did not self-identify as having disabilities (Russell & Malhotra, 2001). In this paper, I excavate the lost story of one such individual: Eugene T. Kingsley, whose legacy spans both time and space. Almost entirely unknown today, Kingsley was born in upstate New York in 1856. He lost his legs in an industrial railway accident. While recuperating in an Oakland, California hospital, Kingsley was politically radicalized and joined Daniel DeLeon's Socialist Labor Party (SLP) to condemn a capitalist system that he saw as unjust and oppressive. He then began an extraordinary, if at first obscure, political career which included two unsuccessful runs for

office in California for the House of Representatives in 1896 and 1898 and later leading his own political organization in Washington State. Moving to British Columbia, Canada in 1902, where he resided for the rest of his life, Kingsley gradually grew in stature. He became editor of an idiosyncratic but important socialist publication, the *Western Clarion*, as well as a printer and operator of a fish shop. He also became a leading member of the Socialist Party of Canada (SPC) and, remarkably, ran for office for both Canada's federal Parliament and the British Columbia legislature numerous times as a candidate for the SPC and later the Independent Labour Party. He was regarded as the pre-eminent leader and the most popular speaker of the SPC in the years prior to 1910 (McCormack, 1977). This article is a synopsis of selected aspects of Kingsley's thought and legacy.

Although there appears to be no existing record of Kingsley's reflections on his own impairments, I believe that his fiery anti-capitalist politics, articulated both in his day-to-day political activities and his electoral runs for public office, was a manifestation of his experiences resulting from the impairment that shaped his life. Occasional comments and initiatives tantalizingly suggest that Kingsley's anti-capitalist dogma was a reaction to how workers injured on the job in late 19th and early 20th centuries in North America were discarded and marginalized by a system that valued only people whose labour could be transformed into profits. In making this contribution, I insert disability politics into labour history, something which has been mostly absent from otherwise landmark social histories (McKay, 2008; Newton, 1995; Palmer, 2000).

This analysis is derived from the social model principle that an inaccessible environment interacts with individual impairments to create handicaps for disabled people. It situates itself within the New Disability History that tries to reassess the life experiences of disabled people within a social model (Longmore & Umansky, 2001; Oliver 1990; Rose 2005). Further, I make the point that throughout his career, Kingsley transcended the reform/revolution dichotomy in espousing completely revolutionary political and economic transformation through electoral means.

### The Early Life of E. T. Kingsley

Little is known about E.T. Kingsley's early life in antebellum upstate New York. However, his upbringing may be placed in the context of a relatively radical geographical space. The 1848 Seneca Falls Convention, which unfolded in a location quite close to Kingsley's birthplace, is justly famous for its call by such pioneering luminaries as Lucretia Mott, Elizabeth Cady Stanton and Frederick Douglass for women to receive the vote and not be subjected to the notorious double standard whereby women's immorality was more harshly judged than male transgressions (Bratt, 1995-96; First Women's Rights Convention, 1995-96).

Although the precise date and details of the extent of the impairment have been lost, Kingsley experienced a railway accident that resulted in the loss of his limbs and forced him to abandon his career in manual labour (McCormack, 1977; Newell, 2008). While recuperating at a hospital in Oakland, California, Kingsley began to read Marx and Engels. He joined the Curacao-born immigrant intellectual Daniel De Leon's doctrinaire SLP which espoused the idea that capitalism could not be reformed but had to be entirely replaced by a revolutionary party that was controlled by the working class-one that could only emancipate itself through its own actions (Buhle, 1988; Campbell, 1999; McCormack, 1977; Newell, 2008). Hence, fol-

lowers were often labeled "impossibilists" compared to those socialists who sought to use the power of the state to enact social reforms, such as pension benefits and workplace safety legislation, which impossibilists tended to see as a sop to stave off working class revolution (Coleman, 1990). In reality, the distinctions between impossibilists and reform socialists at the turn of the 20th century were quite fluid and Kingsley's career manifests this flexibility throughout.

Kingsley quickly developed a reputation in San Francisco as a sharp, street corner orator who agitated against the horrors of the capitalist system. The SLP was at the zenith of its influence on the American Left in the 1890s and had several branches in San Francisco that operated in English, French, German, Yiddish and Italian (Socialist Labor Party, 1896). Along with his comrades in the SLP, Kingsley also challenged the legal power of the state which, at times, attempted to restrict "subversive" free speech on the streets of San Francisco. In October, 1895, the San Francisco Call reported how Kingsley and other SLP activists were arrested for obstructing the sidewalk while delivering speeches at an open air meeting. In keeping with the SLP focus on transforming society through popular education, Kingsley demanded a jury trial at which he was ultimately cleared (Arrested Socialists, 1895; Labor Council, 1895). In other speeches documented from this year, the tensions in Kingsley's political thought are evident. On one hand, Kingsley advocated a radical transformation of society. He remarks in one speech that his vision of socialism did not entail the piecemeal curtailment of specific monopolies but the total control of the government by socialists. Yet, he indicates that the solution for socialists is through the judicious use of the ballot box (Aims of Socialism, 1895). The combination of a maximalist political program with an emphasis on electoral change was emblematic of the late nineteenth and early twentieth centuries.

None of the many articles mentioning Kingsley's political activities in the San Francisco Call ever referred to his disability or his use of artificial limbs and a cane. Yet by the 1890s, there was a well established tradition of prosthetic devices used to assist people who had accidents. As Slavishak has observed in his account of the marketing of artificial limbs to industrial workers in Pittsburgh, the increasing attention devoted to industrial accidents allowed prosthetics manufacturers to expand their horizons from military veterans to injured workers. Four key themes were emphasized: making men whole, the potential for elevated social status upon rehabilitation with a prosthetic, a product of American technological success and a body that could return to wage labor (Slavishak, 2003). Mihm documents how increased emphasis was placed on judging a person's suitability for business or marriage by their physical appearance, citing in particular an article on prosthetic limbs by Oliver Wendell Holmes in the Atlantic Monthly (Mihm, 2002). Williams-Searle notes the importance of masculinity in the construction of railway workers' identities (Williams-Searle, 2001). Given the lack of press coverage, one speculates that Kingsley was able to "pass" as able-bodied and be regarded as whole, an illustration of Erving Goffman's seminal work on passing (Goffman, 1963).

Kingsley was appointed an SLP organizer in California (McCormack, 1977). He was also selected twice to run as the party's candidate for Northern California districts in the House of Representatives. In 1896, he ran in California's Fourth Congressional District and in 1898 he ran in the Fifth District (JoinCalifornia, 2005-2011a; JoinCalifornia, 2005-2011b). Although he received less than four percent of the vote in both races, the fact that a disabled man ran for such an important public office is significant in itself. Eventually, Kingsley and De Leon developed political disagreements over the nature of trade unions resulting in Kingsley leaving the SLP. Kingsley took a highly dogmatic position that trade unions were inherently reformist and

a distraction from the class struggle, while De Leon, although notoriously authoritarian and inflexible himself, had begun to orient himself toward anarchosyndicalist tendencies emerging in the United States (McCormack, 1977). Kingsley subsequently left for the Puget Sound area of Washington State where he joined a group of some five dozen former members of the SLP known as the Revolutionary Socialist League and espoused his purist form of socialism (Schwantes, 1979). In February, 1902, Kingsley was invited by socialist activists to give a speaking tour in Nanaimo, on Vancouver Island (Johnson, 1975). He would settle in British Columbia permanently and go on to become one of the central leaders of the Socialist Party of Canada (SPC), spreading the message of socialism throughout the province and country.

### **E. T. Kingsley and the Founding of the Socialist Party of Canada**

At the turn of the century, class divisions in British Columbia were extreme and famous coal barons, such as James Dunsmuir, were notoriously anti-union. In company towns, workers were obligated to pay exorbitant fees which ate into their meager earnings while living in housing which often featured poor sanitary conditions, spawning disease such as typhoid fever. Some workers labored as much as twelve hours per day, seven days per week. British Columbia mines were regarded as among the most dangerous in the world as companies regularly ignored safety regulations and they experienced a death rate that far exceeded their counterparts in the United States. As McCormack has observed, between 1889 and 1908, British Columbia experienced a shocking fatality rate of twenty-three men per million tons of coal produced (McCormack, 1977).

The British Columbia resource extraction economy, especially at a time when technology had yet to breach the large distances and intimidating geographical barriers separating the population centers of eastern North America from

communities west of the Rockies, was heavily integrated with the American society and British Columbians often were more closely tied to political and cultural developments in Washington State than those in Ontario. Ormsby comments how the American Presidential campaign of William Jennings Bryan in 1896 created more interest in British Columbia mining communities, often populated by recent American immigrants radicalized by militant struggles against mine owners, than did the Canadian federal election contested by Wilfrid Laurier in the same year (Ormsby, 1958). Two speeches by the legendary socialist Eugene Debs to miners in Rossland, British Columbia cemented links between socialist currents in the two countries (Schwantes, 1979). Although an American immigrant, Kingsley, the hardy worker-intellectual, naturally fit in a British Columbia society populated by lumber and mining workers. He rapidly gained a reputation as a fiery speaker. He was appointed editor of the *Western Clarion*, paper of the SPC, and to a leadership position within the party upon its founding in 1904. After a short time operating a fish shop in Nanaimo, Kingsley moved to the then growing city of Vancouver on the British Columbia mainland. He remained there for the rest of his life working in a printing business that he would use to subsidize the *Clarion* until 1912 (Johnson, 1975; Newell, 2008).

The twenty-seven years that Kingsley lived in Canada until his death in 1929 were tumultuous ones from the point of view of the working class and extremely active ones for Kingsley. They encompassed race riots against Chinese, Japanese, and South Asian immigrants on the streets of Vancouver in 1907 (McDonald, 1996), the controversial rejection of hundreds of Sikh, Muslim, and Hindu immigrants attempting to enter Canada on the *Komagata Maru* in 1914 (Parnaby, Kealey, & Niergarth, 2009), a bitter coal miners' strike on Vancouver Island in 1913 that saw the normally aloof SPC temporarily unite with several other left organizations including the iconoclastic Industrial Workers of the World (IWW) to form the Miners' Libera-

tion League (Johnson, 1975), the outbreak of the First World War in that same year and the eventual censorship and suppression of dissidents such as Kingsley and his comrades in the SPC, and the famous Winnipeg General Strike of 1919 (McKay, 2008). These years also featured no fewer than six unsuccessful runs for office for Kingsley: three for the British Columbia legislature between 1907 and 1909 and three for the federal House of Commons in 1908, 1911 and, in his old age, in 1926. Kingsley never came close to being elected (Newell, 2008). However, unlike the American SLP, the SPC did manage to elect a small number of members to the British Columbia Legislature who in fact, for a time, held the balance of power in the provincial legislature. They included the Irish Canadian maverick, James Hawthornthwaite (Seager, 2000). Although Kingsley, who by this point had acquired the nickname "the Old Man," was no longer a central leader of the SPC after 1911 (Johnson, 1975), he joined a proto-social democratic formation, the Federationist Labor Party (FLP), in 1918 and became its Vice-President (Johnson, 1975). He nevertheless retained a radical edge to his politics until his death.

The SPC, led by Kingsley for many of its early years, was from its founding a contradictory political organization, much like the American SLP in which Kingsley played a role in California in the 1890s. On the one hand, it possessed an almost evangelical belief that socialism would inevitably succeed and therefore any sort of compromise with the ruling class was to be avoided. Hence, the impossibilist slogan: No Compromise, No Political Trading that encapsulated the ideology of the SPC (Johnson, 1975). At the same time, on occasion, it demonstrated genuine creativity and flexibility to new conditions. Kingsley travelled frequently on speaking tours across Canada where he addressed large crowds to promote the SPC cause despite his physical impairments. Just as the SLP in California faced restrictions on their free speech, activists in the SPC were prohibited at times from the right to address crowds on Vancouver street corners.

They responded by constructing a raft that they launched in English Bay (adjacent to downtown Vancouver) to serve as a podium for political speeches (Johnson, 1975).

One of the few references describing Kingsley's impairments comes from an interview of SPC stalwart, Bill Pritchard. He recounts an election debate in which Kingsley, a large, bald man, participated. Pritchard depicts Kingsley as having artificial legs and holding on to a chair for balance. When a younger candidate commented that he would leave questions of history and economics to his bald friend, Kingsley replied:

“Ladies and Gentlemen – I’ve addressed hundreds of meetings on this side of the line and the other side of the line – I have never felt it necessary to refer to the physical characteristics of any of my opponents but this young squirt has taken it upon himself to make reference to my baldness – which is very obvious. I want to tell him that there are two kinds of baldness – bald on the outside (he pointed to his head – pointed to the fellow and said) – bald on the inside. You can see my kind of baldness every time I take off my hat – his kind of baldness is evident every time he opens his mouth” (Pritchard, 1969).

Kingsley's printing business, housed in the basement of the now historic Flack Building in downtown Vancouver, played a fundamentally political role in allowing profits to be redirected back to fund the Western Clarion. There appears to be no historic record of how Kingsley managed to access the building. However, as his archived correspondence with Hawthornthwaite indicates, the newspaper had a precarious status and Kingsley constantly had to worry about its financial state. In a poignant 1903 letter asking for two hundred dollars, Kingsley comments, “The Clarion goes under for 30 days and unless the comrades come to their senses, for good. I shall make no further appeal, in fact I’ve made

none so far” (Kingsley, 1903, p. 2). In another letter, Kingsley expresses fear that the Clarion will bankrupt him (Kingsley, 1910). It is a testament to his dedication to his chosen political party that Kingsley was able to keep the newspaper afloat for so many years through subsidies from his printing company. I now turn to a discussion of Kingsley's writings.

## The Writings of E. T. Kingsley

Some of the recurring themes in Kingsley's political writings and speeches are apocalyptic imagery of the fate of capitalism which was expected to collapse within a matter of years and the portrayal of workers in currently existing capitalist society as mere debased slaves without a trace of dignity. Most poignant are references to the physical impact that capitalism has on injured workers. In order to fully understand Kingsley's world view of a century ago, one must get a sense of his colorful language that conveys a world of class struggle that will be unfamiliar to most modern readers. A mainstream Vancouver newspaper headlined an article about a 1908 speech by Kingsley while a candidate for federal Parliament with the blunt title, “If Necessary Let Them Use Clubs.” It quotes Kingsley as stating:

“... [w]ithin the next eight years there will be the greatest upheaval on this western continent the world has ever seen. And if necessary the working classes will go forward with clubs in their hands to emphasize their needs. I hope not. But if necessary, then let them use clubs. The community as a whole must get control of the tools of production” (p. 2).

This article also provides a glimpse into his mannerisms that left such a deep impression on audiences across the political spectrum and made Kingsley so popular during his frequent speaking tours across Canada. Kingsley is described as:

“... a typical American, whose fifteen [sic] years' residence in Canada has not

spoil his accent. He speaks in short sentences, and drives them at his audience with sharp forward jerks of his head. But the most curious of his mannerisms is the way, when wishing to make a point, he licks his first finger, for all the world like a baseball pitcher preparing the famous spit ball. Tall and inclined to be stout, with keen small eyes, that seem to be continually raking his audience for possible hecklers, he is a good speaker with a forceful manner” (If Necessary, 1908, p. 2).

In the introduction to his 1916 book, *The Genesis and Evolution of Slavery*, Kingsley comments:

“The most reckless indifference to the welfare of the slaves of industry is manifested throughout the entire employing world, and not the slightest safeguard is afforded the lives and limbs of the workers, if it can in any way be avoided. Politicians, professors and press writers lie like horse thieves about mundane matters, while pulpiteers weave entrancing fables about the heavenly beyond, for the purpose of chloroforming slaves into forgetting their chains and meekly submitting to the continuation of their crucifixion upon the altar of ruling class plunder” (p. 7).

The book uses the history and structures of exploitation from antiquity to the present day to analyze capitalism. Written without footnotes, it falls within the tradition of popular education of blue collar labourers that was a fundamental cornerstone of SPC philosophy. As McKay observes in his magisterial and path breaking tome of the turn of the century Canadian left, *Reasoning Otherwise*, working class education to foster the people’s enlightenment through an application of science to the world around them was viewed as a core constituent of socialist praxis by a wide range of left activists (McKay, 2008). *The Genesis and Evolution of Slavery* is classic Kingsley and evokes the sharp class contradictions of

the period. His description of workers as slaves is common throughout his published writings and is intended to convey how debased employees are under capitalist wage labour. While brief, the reference to disablement is unmistakable. Kingsley was reticent about discussing any aspects of his personal life in his writings but the tendency for capitalist production to cause workplace injuries that require amputations, the very issue faced by Kingsley earlier in California that caused his own political radicalization, is identified here as a devastating flaw in the capitalist system.

An article published in the short-lived newspaper *Labor Star* (which Kingsley co-founded with Parmater Pettipiece at the end of the First World War, when there was a powerful labor radicalization in Canada) exemplifies the theme of class exploitation and the fluid dichotomy between revolutionary transformation and reformism in this period. He writes:

“So long as [government] can bamboozle or cajole the slaves into docility and quiet under the lash of exploitation, it cheerfully does so, no doubt because that is the cheaper way, but whenever that method becomes no longer effective, the lash, the knout, the club, the gun, the bayonet, the jail and the gibbet are used with equal cheerfulness and aplomb, for, no matter what the cost in brutality and blood, the property rights in human flesh must be held intact to the owners and masters and the game of profitability ruling and robbing slaves must not be broken up” (Kingsley, 1919).

Again, in the strongest possible language, Kingsley condemns the entire profit system and places the blame for this on the property system created by capitalism. Workers are chastised for their docility as wage slaves who will have to rise to the occasion and challenge the more brutal forms of repression that the state will use when it feels threatened (Kingsley, 1919). Nevertheless, the tension in Kingsley’s political thought is

real. Writing well after the Bolshevik Revolution of 1917 replaced the Czarist regime in Russia, Kingsley stresses that in Canada and the United States workers have won the vote. Therefore, the tactics that were justified in Russia are not needed in North America so long as workers have the franchise (Kingsley, 1919). These statements suggest that the boundaries between revolutionary socialism and reform were more fluid and unsettled than they would become in later years.

### Conclusions

In this paper, I have been able to capture only some of the highlights of E.T. Kingsley's long career. Spanning two countries and a series of political parties, Kingsley's life stretched from the antebellum times only shortly after the Seneca Falls Convention of 1848 to the onset of the Great Depression. He was also a disabled man whose political radicalization stemmed from the horrific effects of industrial capitalism on injured workers. Yet in an era long before disability rights were established in law, Kingsley was able to work as a newspaper editor and political candidate, influencing thousands of his readers through his polemics on socialism and the class struggle. Kingsley has left an enormous legacy that future historians will have to analyze for many years to come.

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# Disability and Rehabilitation in Late Colonial Ghana

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**Abstract:** This paper analyzes disability and economic rehabilitation in late colonial Ghana (the Gold Coast), focusing particularly on a program for African soldiers between 1943 and 1947. The project, which attempted to reintegrate the rehabilitees into the existing workforce, failed within a few years of its inception. I argue that its failure occurred for three reasons: urban economic hardship, the rehabilitees' peasant backgrounds and the colonial doctrine of community development. Reinforcing this analysis is the fact that after independence, the Ghanaian government reversed the colonial conditions and achieved much better success.

**Key Words:** disability, rehabilitation, colonial Ghana.

## Introduction

Between 1943 and 1947, the West African War Council (WAWC) and the government of the Gold Coast (colonial Ghana) developed a rehabilitation program for African soldiers disabled by combat injuries during World War Two. The West African initiative drew heavily on the British model of social orthopaedics, which sought to rehabilitate disabled individuals economically by reintegrating them into the existing workforce.<sup>1</sup> The model was "social" in that it defined social citizenship by participation in the labor market; to be a full citizen, that is, one had to be a productive worker. For the British state, expanding the workforce to include those disabled in combat was especially important during the World Wars because military recruitment triggered domestic labor shortages. During World War One, the British government relied on private charities to care for disabled soldiers. In the 1940s the state shifted gears, assuming direct control of the national rehabili-

tation program through the Interim Scheme of 1941 and the Disabled Persons (Employment) Act of 1944 (Cooter, 1993; Cohen, 2001). As we shall discover, the Gold Coast scheme envisioned a similar project of state-directed economic rehabilitation.

Centered in Accra the colony's biggest city, the Gold Coast rehabilitation program sought to retrain the ex-soldiers as productive workers, either by reintegrating them into the urban labor market or placing them in sheltered workshops producing items for sale. Initially, the Accra "Convalescent Wing" targeted soldiers from the Gold Coast Regiment of the West African Frontier Force, best known for its campaign in the Arakan province of southwest Burma (Bourret, 1960; Killingray, 1982; Jackson, 2006). By mid-1945, however, the Wing's patients included soldiers from the other British West African colonies (Nigeria, the Gambia, and Sierra Leone), as well as a handful of civilians (Sponner, 1945, May 15). However, after admitting several hundred trainees in 1944-5, the project faltered and the colonial government abandoned it in 1947.<sup>2</sup> Twenty-four years later, the post-independence government led by Kwame Nkrumah revived the rehabilitation program with more success, extending it to rural areas in addition to Accra and targeting 13,000 formally registered disabled Ghanaians.<sup>3</sup> Although Nkrumah's program deserves to be studied in its own right,<sup>4</sup> for our purposes it is most useful in shedding additional light on the roots of the colonial failure. Our discussion therefore contains two strands. First, we shall assess the failure of colonial rehabilitation based on evidence from the 1940s, highlighting funding problems, poor economic conditions, and the colonial doctrine of community development as the main problems. Second, we shall use Nkrumah's program,

which reversed many of the problematic colonial policies, to reinforce our argument about the failure of the 1940s and to demonstrate that rehabilitation could work under the right conditions.

### **Social Orthopaedics and Soldiers' Rehabilitation in the Gold Coast, 1943-47**

#### **Planning for Rehabilitation, 1943-44**

In early 1943, the Colonial Office convinced the WAWC and the Gold Coast Government to build a rehabilitation unit for disabled soldiers at the Accra Military Hospital (the 37th General Hospital). Reflecting the social orthopaedics model, the WAWC insisted on limiting admission to soldiers with treatable disabilities in order to increase the chances of rehabilitees returning to the labor market (WAWC, 1943, January 16 and 28; Emberton, 1942). This approach reflected Britain's Interim Scheme, which classified disabled soldiers into three categories: those who could return to previous forms of employment, those who could be trained for a different form of employment, and those who could not return to any form of employment (Stanley, 1944, February 28). The British Government excluded the latter, often called "incurables," from the rehabilitation process. In the Gold Coast, Sgd. R. A. Hopple reproduced these categories in a slightly different form, classifying injured African soldiers as temporarily disabled, permanently partially disabled, and permanently totally disabled. Individuals in the first two categories would be taught a trade, while "permanently totally disabled" soldiers would be placed into long-term care or returned to their families. The trades would focus on artisans' occupations, to be pursued individually or in sheltered workshops, as well as clerical work suitable for government employment (Hopple, 1942).

Britain followed up the Interim Scheme with the Disabled Persons (Employment) Act,

which established the right of disabled individuals to participate in the labor market "in a normal competitive environment" (Borsay, 2006, p. 135). The Act contained three components. First, it mandated training and resettlement schemes designed to assess the potential of disabled individuals for reintegrating into the labor market; second, it set quotas of disabled employees for employers; third, it provided for segregated employment at home or in sheltered workshops for individuals deemed incapable of participating in the mainstream workforce. To these ends, the Act called for the development of Rehabilitation Centers and Disablement Settlement Officers to manage the various schemes (Borsay, 2006). In May 1943, the Colonial Office began to pressure the WAWC to implement similar legislation in the Gold Coast. After nine months of discussions, the WAWC and the Gold Coast Governor finally committed to the project in February of 1944 (Stanley, 1943; Stanley, 1944, February 28; Courtland, 1943).

Despite public support from the Secretary of State for the Colonies (Stanley, 1943; Stanley, 1944, March 15), disagreements between the Colonial Office and West African officials delayed the scheme's implementation. For example, the Secretary of State argued that the colonies had an obligation to "resettle" all disabled soldiers "in civil life," including so-called incurables (Stanley, 1944, March 15). The Colonial Office also disliked the emphasis on crafts over standard wage employment (Stanley, 1944, May 16). In contrast, the Gold Coast Government excluded incurables and emphasized craft production. Other sticking points included military versus civil responsibility, staff shortages, and the production of artificial limbs. These problems were intertwined and they reflected the challenge of translating British wartime legislation to the West African colonies. For instance, in the United Kingdom soldiers deemed unfit for service were discharged within 28 days and turned over to the Ministry of Pensions, after which their rehabilitation became a civil responsibility. The War Office wanted the

West African colonies to implement the same principle, but the Gold Coast Government argued that staff shortages would make it impossible. Unless the British Government funded the entire rehabilitation process, after 28 days, the Gold Coast would have to attempt rehabilitation through its existing offices, workshops, and technical schools. The Convalescent Wing would have to be discontinued owing to a lack of resources (Gold Coast Finance Committee (GCFC), 1944). Artificial limbs presented another hurdle. The West African Governments wanted them to be produced at the same standard as Britain's, that is, prostheses with working joints made from metal rather than simple wooden peg legs.<sup>5</sup> To this end, an expert from the limb-fitting firm Hangars visited West Africa and concluded that West African limb-fitters would have to be trained by British experts. This was not possible, however, because of a shortage of British trainers (Shepherd, 1944).

Eventually, the West African vision prevailed regarding craft production and incurables, and agreements were reached to compensate for staff shortages in rehabilitation and limb-fitting. Most importantly, the War Office agreed to subsidize the construction of the Convalescent Wing. When it opened, patients would be discharged from the military after 28 days and the Gold Coast Government agreed to cover the costs of their subsequent rehabilitation. Regarding artificial limbs, Italian prisoners of war with limb-fitting experience would be sent from East Africa to train African limb-fitters at a new limb-fitting center. Britain would fund the Accra limb-fitting center but the Gold Coast would cover the Italians' transportation costs. In addition, the British Government would bring one disabled African ex-soldier to Hangars' workshop for training (Shepherd, 1944).

#### **Implementation and Failure, 1944-47**

With the arrangements secured, the project moved forward in the late summer of 1944. The Italians arrived in August, and on 4 September 1944, the Wing received its first disabled

patients. Housed separately from the hospital, it contained huts, a gymnasium, running track and food store, as well as the artificial limb workshop. By 12 October, the Wing was fully functional, although the limb-fitting workshop had to produce inferior prostheses from local materials until the arrival of limb sets from Hangars in February of 1945. In the meantime, the Gold Coast Government sent a disabled soldier, J. B. Nelson, to Hangars for training (WAWC, 1944, August 1; WAWC, 1944, September 14; Jones, 1944; Burns, 1945). Back at the hospital, in a twist on the British system, as of January, 1945, the military agreed to discharge the disabled soldiers with 28 days' pay as soon as they entered the Convalescent Wing. They were therefore supported entirely by the colonial government, receiving a full disability pension while undergoing rehabilitation (WAWC, 1945, 23-4 January). Two further developments occurred in March. First, the Gold Coast Government considered, but rejected, legislation mandating employment for disabled ex-soldiers after rehabilitation, on the grounds that it did not want to force them into the labor market. Instead, they would be assisted by Resettlement Advice Centers established for all ex-soldiers. Second, after 20 March, the Convalescent Wing began to accept civilian patients (WAWC, 1945, March 8; Robinson, 1945). More than two years after the WAWC proposed the Accra rehabilitation center; it finally had become fully operational.

The Convalescent Wing operated effectively for the first several months. However, on 20 May 1945, the Demobilization and Resettlement Committee of the WAWC reported that the returning soldiers intensely disliked the idea of rehabilitation, preferring to return directly to their homes after medical treatment. To address this problem, the Committee suggested bringing the soldiers' families to Accra in order to persuade more of them to stay for rehabilitation. This did not happen, however, and by late July there were only a handful of patients in residence. On 22 July, faced with a decision to cut European staff, the War Office proposed closing

the Convalescent Wing. Henceforth, disabled soldiers would be treated in existing hospital wings, perhaps with some rudimentary arts and crafts training. On 7 August 1945, the Gold Coast's Commissioner of Labor agreed to close the Wing but not the limb-fitting workshop (WAWC, 1945, May 20; West Africa Command, 1945; Spooner, 1945, August 7). The following March, the War Office took over the building as its new headquarters and the colonial government moved the Italian limb-fitters (who had been freed officially on 24 August 1945) to Korle Bu hospital in central Accra, where rehabilitation facilities were established on much smaller scale (Gold Coast Italian Limb Team, 1946; Burns, 1945). A year later, the government closed the limb-fitting center and the remaining rehabilitation facilities (Gold Coast Legion, 1947).

Hundreds of rehabilitees passed through the Convalescent Wing at its peak between October, 1944 and March, 1945, but the numbers declined precipitously thereafter as the trainees graduated and very few new patients agreed to attend (Spooner, 1945, May 15). Unfortunately, we do not know what happened to the graduates, as there are no records and no indication that the colonial government followed up or even recorded where they went afterwards. It is almost certain, however, that most of the trainees simply returned home after rehabilitation, left to fend for themselves. As such, the colonial project must be considered a failure.

### **Kwame Nkrumah and the Revival of Rehabilitation, 1960-66**

But this was not the end of the story, for the African government of Kwame Nkrumah revived the rehabilitation program after the Gold Coast became independent as Ghana in 1957. Nkrumah "discovered" disability shortly after independence when he began to gather and jail destitutes and beggars, only to find that many of them were disabled. Alarmed by this revelation, in late 1960, Nkrumah recruited John Wilson,

Director of Britain's Royal Commonwealth Society for the Blind, to survey the state of disability in Ghana and develop a comprehensive rehabilitation program. Wilson's recommendations prompted the revival of the colonial scheme and its extension to rural areas. Specifically, Wilson recommended an Industrial Rehabilitation Unit (IRU) and limb-fitting center in Accra, along with eight Rural Rehabilitation Units (RRUs) spread throughout the rest of the country. While the Government developed the Units, registration teams fanned out across the country to register disabled Ghanaians on a regional basis. By the end of 1963, over 13,000 individuals had registered officially (Adoo, 1964). There is no information on their backgrounds, but undoubtedly, more than a few ex-soldiers would have registered during these years.

Like their colonial predecessor, Nkrumah's Rehabilitation Units focused on economic integration. The IRU provided strengthening exercises and basic skills training as a springboard for specialized training in urban occupations. Skills training included carpentry, metalworking, and farm gardening, the products of which were sold to raise money for the Unit (Ghana Department of Social Welfare and Community Development [GDSWCD], 1966). The RRUs offered specialized training for village and town occupations as well as literacy and citizenship classes for peasant trainees. The RRUs' main goal was to produce "all-rounders" in peasant villages, self-supporting and capable of everything from farming and poultry raising to house construction and tailoring, but they also provided training for occupations in rural towns. Taken together, the IRU and RRUs achieved more success than the colonial scheme. For example, in 1963, 56 IRU graduates found jobs, mostly in manufacturing but also in retail and the hotel industry (GDSWCD, 1966). During the same year, a similar number of RRU graduates obtained wage employment in the smaller towns (Adoo, 1964). The graduates provided good publicity for the Rehabilitation Units, as in the cases of Richard Fodzi and S. R. Owusu,

two physically disabled adults who became craft instructors at a middle school after graduating from the Ho RRU. Fodzi remained in his position, while Owusu raised enough capital to become an entrepreneur in Accra (Acquah, 1966). In 1966, the community development journal *Advance* published the stories of twenty-five more rehabilitation graduates of the IRU and RRUs. In addition to their programs at the Rehabilitation Units, they also received support from a variety of other sources, including the Korle Bu hospital, the Accra limb-fitting centre, the Ghana Cripples' Aid Society, and the Presbyterian Church. After graduating, all of the rehabilitees found productive employment in a number of occupations, including craft production, teaching, industry, and trade (Acquah, 1966). In contrast to the colonial program, these stories indicate that Nkrumah's initiative was much more successful.

### Concluding Remarks

The colonial rehabilitation model of the 1940s owed much to Britain's emphasis on economic reintegration. Under the British paradigm, rehabilitation sought to "normalize" ex-soldiers disabled from wartime injuries by reintegrating them into civil life through vocational rehabilitation. The British rehabilitation scheme targeted ex-soldiers with any form of physical disability, including but not limited to cartilage injuries, amputated limbs, blindness and paralysis (Great Britain Ministry of Pensions, 1942; Watson-Jones, 1942; Anderson, 2003). Under the rehabilitation model, the British Government did not consider disabled ex-soldiers true citizens until they became productive workers. The British Ministry of Pensions and the Colonial Office expressed this idea explicitly during the discussions about the Accra Convalescent Wing. For instance, in 1942 the Ministry of Pensions told the WAWC that "rehabilitation aims at restoring patients to their full wage-earning capacity in the shortest possible time" (Great Britain Ministry of Pensions, 1942, p. 1). Two years later, the Colonial Office referred to

this process as "resettlement in civil life" (Stanley, 1944, February 28, p. 1). The WAWC and the Gold Coast Government accepted this model, seeking to normalize disabled soldiers by retraining them as workers. The GCFC, for instance, referred to this program as "the process of returning the disabled man to civil life—a process which entails in cases where medical treatment is unable to fit a man to return to his previous occupation, a special training designed to equip the disabled man to live as full and as useful a life as possible" (GCFC, 1944, July 25, p. 1). This statement clearly linked civil life to economic productivity and rehabilitation.

As it happened, this vision was incongruent with the social background of the disabled ex-soldiers, most of whom had been recruited out of the rural peasantry. What chances would they have had in 1940s and 1950s Accra? Rehabilitation along British lines would have been difficult due to the peasants' lack of formal education, and, for those who graduated, the poor state of Accra's labor markets would have undermined their chances of success. Jobs were very scarce and the colonial governments did little to assist any soldiers, much less disabled rehabilitees. Furthermore, outside the highest ranks of the civil service, the jobs that did exist failed to provide adequate living standards. Consumer goods shortages and inflation meant that prices outstripped wages, which made it very hard for urban workers to make ends meet (Killingray, 2007; Cooper, 1996, 2002; Gocking, 2006). Sheltered workshops would not have provided an alternative because the average African urban citizen would have had little, if any, disposable income to spend on crafts. In short, rehabilitated peasants would have had an immensely difficult time finding gainful employment.

Beyond the colony's poor urban economic conditions, the colonial philosophy of African development actually opposed the transformation of peasants into workers. From the mid-1940s, just as rehabilitation arose as a colonial project, the Gold Coast government was devel-

oping the notion of community development for the African population. Under this doctrine, communal African social structures were to be protected against the disintegrative effects of capitalist development, including “Westernization” and individualism (Cowen and Shenton, 1996; Grischow, 2006). This model had its roots in the earlier doctrine of indirect rule, in which the colonial state codified the power of chiefs as trustees over their communities (Phillips, 1989). Community development sought to modernize this system by absorbing the educated elite into village politics, but the goal of protecting African communities from modernization and individualism remained intact. Indeed, it intensified in the face of labor resistance and increasing African anti-colonial nationalism. Therefore, although community development sounded similar to rehabilitation in its drive to develop “the individual in society,” the doctrine defined “society” in terms of traditional African communalism rather than modern individualism (Hilliard, 1955a, p.27). In short, colonial development doctrine sought to block rural Africans from becoming wage laborers. Instead, “real West African progress” (Hilliard, 1955b, p.40) would occur only if individual Africans remained bound to their communities as “subjects” of their chiefs rather than “citizens” of the nation (Mamdani, 1996). With its roots in capitalist labor regimes, economic rehabilitation directly contradicted this project.

Summing up, the colonial failure to translate British social orthopaedics to the Gold Coast occurred for a number of reasons, including funding and staff shortages, poor wartime economic conditions, and, especially, a doctrine of community development that opposed the transformation of “traditional” Africans into modern workers. The subsequent experience of Nkrumah’s disability program reinforces this argument, while showing that rehabilitation could succeed if these factors were reversed. Unlike colonial officials, Nkrumah did not worry about preserving traditional African communities against modernization and wage labor. In fact,

he wanted to recruit 1,100,000 Ghanaians into the workforce as part of his drive for socialist industrialization (Ghana Office of the Planning Commission, 1964). Rehabilitation would allow Nkrumah to integrate disabled Ghanaians into this project, contributing to national development by unlocking their economic productivity. To this end, the Government absorbed rehabilitation into the paradigm of community development – the opposite stance of the colonial governments of the 1940s. Furthermore, Nkrumah did not face funding or staff shortages because, as of 1964, his government controlled £43,000,000 in reserves inherited from the British Government (Omari, 1970), which prior to 1957 had been held in London, unavailable to the colonial governments of the day. This was more than enough to cover the £165, 000 cost of the rehabilitation scheme (Wilson, 1961). In addition, the rehabilitees faced relatively better job prospects than the ex-soldiers of the 1940s, because Nkrumah created a host of state-owned factories, as well as a number of state farms (Omari, 1970). In short, Nkrumah’s successes of the 1960s shed light on the colonial failure, while demonstrating that rehabilitation could open the door to productive employment for disabled Ghanaians.

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## Endnotes

- <sup>1</sup> This section is based on Borsay, 2005 and 2006.
- <sup>2</sup> Details of these events, which are discussed below, can be found in the Public Records and Archives Administration Department, Ghana (PRAAD), CSO18/5/23: Disabled Soldiers Rehabilitation 1941-4 and PRAAD/CSO/18/5/24: Disabled African Soldiers – Rehabilitation and Training of, 1944.
- <sup>3</sup> Ghana became independent from Britain in 1957.
- <sup>4</sup> See for example Grischow, 2011.
- <sup>5</sup> For a concise discussion of the historical development of prostheses, see Le Vay, 1990.

# Disability Studies Pedagogy: Engaging Dissonance and Meaning Making

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## Research Articles

**Abstract:** Student responses to disability studies pedagogy are influenced by the context in which they learn. This study examined student responses in two disability studies initiatives: one within a teacher preparation program that included American Indian students, the other within a stand alone, interdisciplinary course taken primarily by Americans of European descent. Course dialogue and students' written assignments were used to identify and categorize their responses. While some students readily engaged in critique of disability as culturally constructed, experiences of significant resistance related to positivist filters, adherence to individualism, and defense of identity-related norms. These responses are discussed as considerations for more effective pedagogy in this relatively new field.

**Key Words:** disability studies, critical pedagogy, student response

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Anticipating student responses is essential in developing disability studies pedagogy. Ultimately we hope to foster shifts in position and cultivate allies in the movement to transform dominant notions of disability. As a critical pedagogy, it is expected that student responses will include a mix of dissonance, as well as solidarity. Few studies have been conducted to directly examine this process within the field of disability studies (Cypher & Martin, 2008; Kniepmann, 2005; Thomson, 1999). In this paper, we reflect on student responses within two disability

studies initiatives, each at a different institution. One initiative was embedded within a teacher preparation program that primarily consisted of American Indian students; the other initiative involved a stand alone, interdisciplinary course taken primarily by white, traditional age students. Each of the researchers was involved in teaching or developing the disability courses examined in this paper. The different contexts allow us to examine a range of student responses. As expected, students in the former situation generally embraced the opportunity for cultural criticism, while many students in the latter situation were significantly challenged by the questioning of dominant assumptions. In this analysis, we categorize and describe student struggles and engagement with the concept of disability as culturally constructed and discuss the implications for disability studies pedagogy.

Our approach to disability studies is grounded in sociology (Bogdan & Biklen, 1977), cultural studies (Hall, 1997), and critical pragmatism (Burbules & Berk, 1999), recognizing that disability is socially constructed through forces of knowledge and power that create oppression and exclusion. Disability studies does not deny that there are differences, either physical or mental, between people; rather, the significance of these differences takes on meaning within particular discourse, social institutions and practices (Bogdan & Taylor, 1994). Our aim is to foster a framework for inquiry that identifies oppressive discourse in the context in which it is formed, coupled with a determination for social change (Dewey, 1927). This approach is distinguished from disability studies

scholarship located in literary criticism and the humanities, which has less emphasis on forms of social power and advocacy (Abberley, 1999, p. 693). As a foundation for understanding students' responses, we begin with an explanation of our underlying assumptions about disability studies and considerations related to the learning context.

## **Disability Studies and the Learning Context**

Our pedagogy is built upon the following three assumptions: (1) meaning is culturally shaped through shared experience; (2) power operates within culture to institutionalize certain values, practices and structures; and (3) culturally shaped oppression can be transformed. We adhere to the concept that transformation of oppressive discourse involves identification and rejection of associated assumptions, beliefs, practices, and structures. It is not adequate to simply reveal social injustices or focus on specific alternative outcomes, such as inclusive education. Substantive change requires understanding and explicit rejection of that which contributes to the injustice. As noted above, our aim is to give students a framework for and experience with critical inquiry, as an ongoing process. This goal is in line with Dewey's (1927) notion that democracy is the development of social intelligence. Through enduring the consequences of our actions, we adjust our thinking to generate increasingly rich and better experiences. Personal and social change are essential aspects of the process, as we are all implicated in the production and reproduction of cultural meaning and practices.

Our conception of criticality is different from the conventional approach to critical thinking which emphasizes the acquisition of cognitive skills, such as diagnosing invalid forms of argument and knowing how to make and defend distinctions. We do not find it sufficient to change individual thinking habits without challenging institutions, structures, ideologies,

and relations of power that have engendered distorted thinking in the first place. Criticality "is recognized as having conscious political intentions that are oriented toward emancipatory and democratic goals" (Quantz, 1992, p. 448 - 449). Therefore, it does not simply engage in criticism (a charge critics have leveled against post-structuralism), nor does it peruse unreflective, uncritical "practical" social action. Our view is that unless students are thinking within specific socio-political and ethical contexts, generalized critical thinking simply enshrines many conventional assumptions in a manner that often teaches political conformity. We believe that criticality is a pedagogical practice, a definition of what we do and whom we are, not simply how we think (Burbules & Burk, 1999). As such, each of the authors has personal experience with disability and/or efforts to effect change in disability services, education, policy, and a variety of community contexts.

With the goal that students critically examine cultural assumptions, structures and practices, resistance is expected. The literature on critical pedagogy emphasizes students' beliefs and identities as a source for understanding this resistance (Ellsworth, 1989; Britzman, Santiago-Valles, Jiménez-Muñoz, & Lamash, 1993; Janks, 1995; McKinney & van Pletzen, 2004). Students' investment or identification with disability-related norms will certainly influence their engagement with critique. We argue for consideration of at least two other major sources of dissonance and resistance. Most important is acknowledgement that a culturally constructed world view is fundamentally different from the dominant, positivist view in which knowledge is considered objective and outside of ourselves. For most students this way of thinking is taken for granted. It is a habit of mind and by definition not open to question. Even for those who are open to understanding the social construction of knowledge, it is rarely a quick or complete transformation. Students' openness is also likely to be influenced by situational factors such as time to attend to the complex-

ity and challenge of considering fundamentally different beliefs and ideas. Related to this, the educational context in which they are encountering disability studies is an important factor to consider. Students in the teacher preparation program that was part of this study had the advantage of being immersed in the ideas over time and focused within a specific discipline. Students who are taking a stand alone course have the challenge of interpreting cultural critique of disability within the framework of their major discipline and other coursework. Some students come to disability studies with experiences, beliefs, identities, and situational factors that leave them open to cultural critique. For them, disability studies can be empowering and can contribute to the development of their criticality. For most students, the expectation of disability-related cultural critique can range from a potentially transformative experience to one of confusion, dissonance, and even defensiveness.

While much of the literature on critical pedagogy points to the importance of facilitating student self-reflection, consideration of the context in which they are learning may suggest a less targeted approach, at least initially. At an introductory level, opening the classroom to student reflection and personal beliefs can act to privilege the dominant notions they are likely to hold. While student-centered teaching is aligned with critical pedagogy, it is not effective if it reinforces dominant positions. Even when presented with narratives, perspectives, and information that challenges their beliefs, students who are highly invested or immersed in dominant ideologies are likely to reject or re-interpret them within this framework (Festinger, 1957).

A number of critical theorists suggest a directive approach to counter dominant positions. Dewey (1927) argued the importance of giving advantage to marginalized voices and perspectives in the democratic process. More specific to the learning process, Gramsci (1973) emphasized the importance of exposing students to a body of theoretical work through didac-

tic means if necessary. Similarly, Willingham (2007) suggests that a fair amount of content knowledge increases the likelihood of developing critical thinking. Though disability studies is grounded in a democratic and constructivist approach, student characteristics and other contextual factors may call for a more directive approach prior to open learning.

The risk, however, with being too directive is that students will adopt the mechanics of critical inquiry without the opportunity for involvement in it as a change process. Flores (2004) cites the following cautions:

“There is no doubt that students can be taught to examine words for political meaning and to criticize the values that lie beneath the text, yet the risk is real that students are trained to produce a reasoned critique that is neither individually transformative (Graff, 1990; Seitz, 1993; Horner 2000) nor that brings change in student practices or aspirations (Janks 2002)” (The Risk of Simplistic Binaries section, para. 2).

The challenge with disability studies pedagogy is to consider the contextual factors in which students are learning. In situations in which there is a short time frame and high student resistance, they may benefit from the opportunity to gain and process content knowledge, without the expectation(s) of open response or personal application that could be threatening. This does not mean that student resistance should be suppressed. Rather, as students inevitably assert dominant notions of disability, alternative perspectives and information can be readily referenced and used to criticize, problematize, and complicate those points of view in the struggle for new meaning (Giroux, 2001; Flores, 2004). The opportunity for active personal engagement in cultural criticism should be available to students as it is meaningful to them. As McKinney and van Pletzen (2004) conclude:

“Such change takes place in haphazard, non-linear ways in relation to a multitude of experiences, rather than a single semester university course... Thus pedagogy for change, both of the self and of the social, may translate at the level of the classroom into aiming for moments of significant intellectual engagement in issues of social inequality and representation” (p.169).

In this article we describe a range of student responses to disability studies and the contextual factors that influenced their learning. Emphasis is placed on student responses in the stand alone course, as this is an increasingly common scenario in the early stages of the field. These students more clearly reflect the dissonance, as well as opportunities for change, that we will benefit from understanding. Responses of American Indian students in the teacher preparation program validate the importance of and possibilities of sustained inquiry that is in solidarity with those who have experienced marginalization. Together, the different contexts allow us to explore several tension points and opportunities for facilitating students’ involvement in transforming oppressive disability discourse.

### **Research Contexts and Data Collection**

We examined student responses to disability studies at two different colleges. Both institutions were small, liberal arts colleges located in the Midwest. At Institution A, disability studies was offered as an introductory course through the Interdisciplinary Studies Program. Students were sophomores through seniors with various majors, including education, paralegal studies, and communication studies. Class sizes were small, ranging from 9-16 students. The students were predominately traditional age European Americans and none of them had studied disability from a critical framework prior to taking the course. At Institution B, disability studies was the emphasis of a teacher preparation program in special education. It was offered in a hybrid

format that included class meetings as well as online learning. The program was designed for a cohort of 16 students, half of whom were American Indian, one was Hmong, and the others European Americans. While the two initiatives differed in terms of design, length of study, and disciplinary location, they were grounded in the same theoretical framework as described in the previous section and offered similar content which included personal narratives, a framework for inquiry and cultural critique. We also used collaborative teaching which we believe was of significant value in listening, clarifying, supporting, and challenging students. Most important, the approach reinforced the collaborative nature of the meaning making process.

Personal narratives including readings, videos, and discussions with disabled people were used as grounds for understanding the need for change (Bogdan & Taylor, 1976; Longmore, 2003; Mooney & Cole, 2000). They challenged essentialist notions of disability, allowed for perspective taking, and provided students with exposure to the social injustices related to disability on a personal level. As noted above, however, revealing social inequities will not necessarily bring about change (Ellsworth, 1989; Britzman et al., 1993; Janks, 1995; Granville, 2003). Students were provided with the opportunity to learn about culturally shaped meaning (Hall, 1997) and inquiry through text analysis and examples of cultural critique (Baynton, 2001; Davis, 1997; Gould, 1981; and Oakes, Wells, Jones & Datnow, 1997). We used text analysis (Rousmaniere, Quantz, and Knight-Abowitz, 1998) as a model and means of inquiry using three essential questions. How is disability represented in our schools/culture? In what contexts have constructions of disability arisen (e.g. historical, economic, political factors)? What are the moral, political and value positions that maintain these representations? This line of inquiry was used throughout our courses in readings, discussions, and projects to explore a variety of disability related issues and topics.

Using this line of inquiry, we cultivated criticality and opened up the possibilities for envisioning social change. A few specific strategies were used in the stand alone course in the effort to engage students who had more traditional backgrounds and potentially higher levels of resistance. For example, the cultural construction of beauty was explored as a likely means of engaging them in critique on a personal level. This provided the opportunity to understand how meaning is shaped in a way that is consequential to them and to make a connection with disability related norms (Garland-Thomson, 1997). We also used a number of collaborative and dialogue-based strategies to aid in both interpreting course readings and sharing their understanding (Fitch & Hulin, 2008). A major strategy was the expectation that students conduct cultural critique on a disability related issue of their choice. While the text analysis framework challenged them to conduct cultural critique, the option to select an issue allowed them to do so at varying levels of personal implication. Self-reflection was not required in the analysis. We did not expect that all students would achieve critical thinking or transformation, but aimed to provide a foundation of knowledge and a framework for analysis that would make meaningful involvement possible.

We used ethnographic methods to collect data including participant observation, analysis of student assignments and classroom discussion. Data collection occurred over a period of two course terms and involved the use of reflective field notes that focused on students' dialogue and the questions they raised in class and in individual meetings. We relied heavily on analysis of students' written work. Our primary purpose was to contextually describe points of dissonance and connection in students' responses to disability studies.

The following sections describe four significant categories of responses by students as reflected in course dialogue and their written work. The four categories include: (1) positivist

filters: objectivity and blame; (2) power of personal narrative vs. adherence to individualism; (3) identity: a source for challenging or defending disability related norms; and (4) moving from criticism to criticality. All students, whose work is referenced, provided formal permission to use their responses in this article. Pseudonyms are used throughout.

### **Positivist Filters: Objectivity and Personal Blame**

A positivist epistemology is the foundation of dominant notions of disability. Positivism is the belief that meaning is objective and universally valid. It is the view that meaning exists externally, and independently, in the "thing-itself" and thus transcends time as well as culture (Kincaid, 1996). The dominant scientist/positivist discourse strives to eliminate value-oriented questions and regards fundamental normative and ethical questions as strictly personal. This values-free or neutral position effectively individualizes and depoliticizes social justice issues, such as oppression associated with disability, reframing them as micro and personal rather than macro and structural. Students' adherence to knowledge as objective truth and the tendency to personalize disability issues were a source of significant struggle and misunderstanding among those in this study.

On a basic level, there was literal confusion with course readings as students misinterpreted authors' cultural criticism as objective statements. For example, after reading an article by Lerner in which he critiques meritocracy, a student stated, "Lerner believes that our society is based on merit." After reading Hall's article on representation and meaning, another student summarized his concept of naturalized meaning with confusion, "Stuart Hall says that social power means that, 'This is just the way things are, get used to it, we'll never change this.' If that is true, then the world really will never change and people with disabilities will always have problems accessing things, getting good

jobs... and that is not true.” This level of confusion made it essential to use reading guides and structured dialogue to clarify the meaning of course readings and content.

As they were guided to view meaning as socially constructed, many students held to the notion of phenomena as fixed and subject to right/wrong interpretation. Students commonly made statements such as, “The way that we, as a society, see something may not be the right way to see it.” In her final paper, another student concluded, “Disabilities, sexual orientation, race, age, and gender are all things that we socially construct. We give each of those things a certain meaning. It doesn't mean we give them the correct meaning. We give those things meaning by having those meanings be opinion-based.” Students also commonly held to the notion of disability labeling, with the two common claims summarized as such: (1) there is no alternative to formal disability labeling, and virtually nothing to be done about informal labeling; both are inevitable and natural and (2) the stigma of formal disability labels (“exceptionalities”) stems from myth and personal ignorance; correctly understood they are actually beneficial and necessary to adequate funding and the equitable distribution of resources (Fitch, 2002; in press). One student, who cited strong consequences of labeling in the educational system, still held to the fixed nature of disability and thus, the inevitability of labeling. She wrote:

“I do understand that there are students who have learning disabilities and require more help than others. This issue is not that the student has the disability and needs more help with her or her studies, but whether or not the educational system has done all it can to insure that it has explored all the alternatives before labeling the student with a disability.”

As instructors expected, when students, who were positioned in the positivist framework, engaged in cultural critique, they did so in the form of personal blame. According to Seas (2006),

students tend to adopt the binary of us vs. them if they have not learned to see themselves as part of the construction of knowledge. As they came to see disability related norms as oppressive, students commonly personalized and situated responsibility outside of themselves as reflected in statements such as, “People are programmed to the normal,” “The Special Olympics makes disabled people out to be outcasts,” and “We are convinced to pity those with disabilities and to be thankful that we’re not like them.” A tone of blame was evident with statements such as, “How would we like to be called names such as idiot and ugly? We wouldn’t like it very much... It’s not fair to those who are disabled to be the butt of jokes.” Even though this student described herself as participating in negative responses, she viewed this as other than human. She stated, “We are convinced to be rude, mean, judgmental, embarrassed, and to act like we are better. This is how wrong our society and media are - to convince us to be such monsters.”

Students’ position of personal blame in attempting cultural criticism shifted to one of neutrality when issues in which they were invested were called into question. For instance, one student who supported segregated education concluded, “Kliewer and Biklen warn of the social consequences of labeling. Others argue against the dangers of full inclusion as it may detract from the education of those not labeled with disabilities. It is reasonable to assume that they are all correct to some degree.” Another student, who described herself as benefitting from educational tracking, responded to the Oakes, Wells, Jones, and Datnow (1997) critique of privileged positions associated with this practice as follows, “I believe there is no wrong party in this debate and that every parent, teacher and school board member is trying to accomplish what they thought was best in the situation.”

The challenge in meeting this basic level of resistance is to make explicit the contrasting assumptions underlying positivist and cultural studies discourses. The identification and re-

jection of oppressive discourse needs to be distinguished from the issue of personal blame if we expect students to openly engage in critique and take responsibility for change. This level of understanding was developed in students who made statements such as, "Often these views of people with disabilities are not meant with malevolence, but they do oppress the disabled community." Andrzejewski (1995) suggests countering blame through constant attention to the structural and discursive social construction of dimensions of knowledge, by asking students to understand why things occur and what macro forces shape their knowledge. In the effort to raise the personal to the social, however, narratives of those who have been marginalized are essential.

### **Power of Personal Narrative vs. Adherence to Individualism**

Cultural critique relies upon the perspective of disabled people as a source of countering dominant norms: identifying misconceptions, exposing their consequences, and understanding that which is equitable and just. A challenge in promoting personal narrative as a means of social understanding was students' equating this with adherence to individualism and personal truth.

A number of students maintained the legitimacy of dominant practices such as Special Olympics, tracking, segregated education, and congregate residential services based on notion of individual choice and individual needs. Their assertions were grounded in the claim that they personally knew people who experienced these practices as positive. In response to personal narratives that supported inclusive education and community living, students asked, "Do all people with disabilities and their families take this position?" "Don't some people need specialized residential settings?" While students were open to inclusive education and community living for some, many concluded that the segregated options should also be available. In the words of

one student, "Simply put, both self-contained education and full inclusion can work in harmony on a case-to-case basis in order for students to receive the education they are entitled."

This becomes a particularly complex issue related to disability in that the concept of "individualized" needs has been used to justify inhumane and unacceptable practices (Bogdan & Taylor, 1994). In line with critical pragmatism, we did not want to define acceptable practice. We did, however, want to promote the notion of continual interrogation of practices for the purpose of identifying and resisting those which are oppressive. This process must be grounded in knowledge of consequences to individuals, and within a framework of critical inquiry and social change.

In this effort, we exposed students to critical perspectives and posed questions about how those perspectives that are not critical are culturally shaped. For example, consider the student who argued for continuum of educational placements. His argument was based on the perspective of a man, who he supported, and who claimed he would have benefitted from more specialized, even segregated education where he could have learned skills such as interviewing strategies, needed to secure a good job. In addition to referring to narratives that were critical of segregated education, we posed a series of questions such as, "Did he need a segregated setting to get this?" A number of class members raised the issue that many typical students graduate without knowing how to interview for or secure a job. We continued with the questions, "What is the root of this underlying notion that real life skills are non-academic?" and "What would education look like if it were more meaningful for all of us in that respect?" Students' answers to the latter question provided a rich opportunity to understand the value of raising personal issues in the broader social context. Their tone was enthusiastic as they used the negative experience of disabled students to re-imagine edu-

cation that would benefit them all. As Tingle (1992) argues:

“...the wish to feel at home in the world is not the expression of a delusion, or as Freud might have it of humanity's naive self love; it is the expression of a profound human need. What radical pedagogy must, instead, aim to do is to transform this need from a grandiose expectation into the desire to create a world in which all may feel at home” (p. 88).

A number of students shared stories of taking action in support of disabled friends and family members. One student had a brother with cerebral palsy who died a few years ago. Despite needing round the clock nursing care, his mother was committed to keeping him at home. The student shared several stories of how he challenged his friends to relate to his brother as a competent peer, someone to “hang out” with. For example, though his brother did not move or communicate except to make simple utterances, he laughed when the student got into trouble – a typical sibling behavior. Another student who had a disabled friend told stories of how he confronted people who focused on his friend's differences, asking them to get to “know him as a person first.” These students' stories demonstrated action to transform images of disability; yet, their determination for change remained within the realm of the personal. Both students seemed guarded against viewing their situations in a broader social context. The latter student spoke to us outside of class and explained that he was worried he was “using” his friend by holding him up in the learning process. Both were uncomfortable with their situation being seen as anything beyond a personal matter - being a good friend, or good brother.

Feminist theory provides a rich source for understanding the tendency to adhere to personal experience. Brown (1995) argues that this type of feminism:

“... betrays a preference for extrapolitical terms and practices: for Truth (unchanging and incontestable) over politics (flux, contest, instability); for certainty and security (safety; immutability, privacy) over freedom (vulnerability, publicity); for discoveries (science) over decisions (judgments); for separable subjects armed with established rights over unwieldy and shifting pluralities adjudicating for themselves and their future on the basis of nothing more than their own habits and arguments” (p. 37).

To the extent that students rely upon individualism and authenticity of personal experience, they are free from struggling with disability as a more complicated social and political issue.

### **Identity: A Source for Challenging or Defending Disability Related Norms**

Identity has been a central focus for understanding students' responses to critical pedagogy. Bauman (2007) argues, “Identity owes the attention it attracts and the passions it begets to being a surrogate of community: of that allegedly 'natural home' – that natural home of non alienation” (p. 107). Students who have been marginalized by cultural norms readily challenged them as a means of connection. They recognized the social construction of identity and the importance of using the perspectives of those who have been marginalized to construct a just or inclusive society. For many students, however, their sense of “who they are,” was constituted by traditional notions of disability. Challenges to these norms represented a threat to their self and place in the world.

As expected, a number of students were directly involved in practices that were subject to examination and critique within the course, such as providing congregate and segregated services or participating in educational tracking. On several occasions critique expressed in readings or

class dialogue seemingly called into question the identity of students who defended the practices; some responded strongly and with emotion. For instance, in a class discussion of Foucault's concept of a hierarchy of control, we examined behavioral management strategies that have been considered acceptable practice such the use of isolation rooms. One student described how schools strong arm students by using "big men" to carry out these practices and explained that "he was one of those men." According to him, the people he works with are "severely disabled" and that "these people need time out." He was critical of his role, but defended the practice. On another occasion, we were discussing the history of institutionalization and its roots in medical discourse. Two students, nursing majors who work in a residential setting for children, were visibly upset. They described their work setting to the class and claimed, "But these children are happy. You should see this place, it is like a home. We make it like home, we're all family." After class they asked if they could conduct an analysis on the importance of residential settings.

One student responded particularly negatively to a reading by Oakes, Wells, Jones, and Datnow (1997) on educational detracking in which the authors deconstruct the practice. This was not the same student cited in the above section. In a written response, this student argued:

"She (Oakes) merely ranted on for fifteen pages about the so called inequities put into place by the 'white elite.' Oakes neglected the issue at heart, detracking, to rant about the social, economic and racial difference in America. I feel she could have written a more convincing passage if she had omitted the slanderous accusations of inequities imposed by the 'white elite,' and focused on how all students would benefit from detracking...."

The affective response by this student may be attributed to the fact that the concept of "white elite" challenged her identity at a more basic lev-

el than challenges to work based practices others faced. Tingle (1992) concludes that strong responses from students seem to be arguments for their selves, conceived as something distinct from their particular social roles. He claims this to be particularly true if students conceive of their beliefs as "self-objects." He explains:

"In this case, the sort of control students may expect to have with respect to their beliefs may more resemble the sorts of control they expect to have over the parts of their bodies or the thoughts in their minds. Those challenges to beliefs which suggest that they might be reexamined may be experienced by the student as a challenge to his or her self-objects and concurrently his or her control over these objects. It is as if to say some outside force had suddenly laid claim to a territory one had previously regarded as under one's own control. Students may indeed feel, with respect to challenges to their beliefs, much the same sorts of feelings of embarrassment and even shame that one might experience before suggestions that one's nose is too long or one's body too fat" (para. 18).

Perhaps the strongest identity-related response came from an African-American student who expressed tension and resistance throughout the course. His resistance centered around the association of disability with discrimination. He argued that disability was real and "somebody would be crazy to mistreat someone with a disability." Acknowledging the sensitivity of this issue, I simply took opportunities to engage the class in examining the intersection of disability with race, including incorporating the work of Keith Jones, a disabled, African American activist. The student made this the focus of his text analysis; yet, the majority of his critique focused solely on race. In his analysis, the student wrote: "Although there have never been signs or documents stating that people with disabilities could not enter restrooms, use water foundations, or

eat in restaurants, discrimination is still an issue. More subtle ways to keep people that are physically or mentally impaired out have been used, such as not making a building wheel chair accessible.” Then he quickly shifted to a discussion of discrimination related to African-Americans in a way that was fragmented from disability. The student wrote:

“African Americans weren’t really allowed to do much as U.S. citizens. Amendments had to be passed before they could even vote. Violent acts were normal. The word discrimination doesn’t fairly describe what the African American race went through.”

He continued to describe the major events in the fight for African-American liberation, as well as his personal experience with “acts of prejudice.” Using his paper to recount and distinguish the injustice experienced by African-Americans, this student almost completely cut himself off from cultural critique of disability.

The responses of these students point to the complexity and potential of creating challenging, yet safe and engaging space within disability studies. Students whose sense of identity is open to the social construction of self will be affirmed or challenged to redefine or reposition themselves. Students made comments such as, “this course helped me understand myself as a person.” Those who are resistant to this notion will accept as ‘truth’ only that which reaffirms their limited conceptions of self (Sedgwick, 1990) or will experience threat to self.

Disability studies pedagogy will likely affirm or challenge identities and thereby demands careful consideration. One lesson, as noted above, is to closely guide students in critical readings. Unlike with other readings, the assignment associated with the Oakes, Wells, Jones & Datnow (1997) article was relatively open, asking students to simply connect the authors’ arguments to other course readings. Guided questions would likely have assisted all students to interpret the authors’ points more construc-

tively. Is it sometimes more constructive for students to focus on issues in which they are less invested, at least in the initial phase of developing criticality? Two of the students mentioned above conducted thoughtful analyses in their papers, focusing on issues in which they were less invested - children’s literature and film.

## Embracing Criticality

Some students seem to flow through the courses, learning to describe and identify representations of disability in terms of their historical roots and contextual factors. Some of these students were already critically positioned, as was clearly the case for American Indian students who saw immediate parallels to their history. For those with minimal prior reflection on disability issues, their level of criticality developed as they explored issues through readings, writing, class activities and dialogue. These students readily identified social injustices and applied critical analysis to issues which included labeling, physical accessibility, community living, group segregation, and other forms of oppression. These students were engaged in transformation.

Many students in the teacher preparation course drew upon their history with injustice to understand disability related injustice. For example, one student made the following reference, “Labeling of indigenous peoples started as a policy in 1782 or thereabout, during the First Continental Congress; suggested by a statesman named James Duane, an attorney also. He declared ‘psychological warfare’ and so began the use of the derogatory word of ‘Sachem’ in reference to our Sacred Medicine People.” Another student elaborated:

“Native people have had much the same treatment as people with disabilities in the area of negative language. Instead of staying that ‘Indian girl,’ just say ‘the girl’ or better yet use her name. Being Indian, just as being a person with a dis-

ability, does not relegate someone to a certain category of person. Negative stereotypes of Native people have plagued them, much like people with disabilities. Changing our language for the positive will have positive and lasting impact.”

Moving beyond the issue of language, these students described their future roles as “standing up for the rights” of others and as change agents in the educational system with the intent to build membership in classrooms and use responsive instructional practices.

In the stand alone course, a number of students demonstrated criticality in their final papers. One student chose to examine accessibility in her own apartment complex. She chose this issue because of a sense of responsibility in her own living situation. After observing a lack of accessible parking spaces, curb cuts, and entrances, she engaged in a process of inquiry that evolved through use of the text analysis framework, reflections, and class dialogue. She contacted the residence staff and management on several occasions, asking, “What are the existing barriers for a resident who uses a wheelchair or an assistance dog? What about a visitor? What does the ADA require?” Class members were interested in her findings, especially when she reported that residence staff was surprised and increasingly irritated at her questions. Since barriers to physical accessibility are relatively easy to see, this proved an important point of reference for drawing the class into the critical process. This student’s act of interrogation led class members through a line of inquiry, including questions such as, “What was their rationale for lack of access? Whose interests are served by not creating access? Where does power lie in this situation?” She concluded, “Everything from not having accessible buildings, accessible parking, not having curb cuts to get from the street to the side-walk, or vice-versa is all a way of ‘normalizing’ the fact that people who use wheelchairs are not welcome here and do not live on the property.” This student seemed empowered that

she had brought this issue into management’s consciousness.

Another student, an education major, analyzed her experience working as an instructional assistant to a girl who was in the process of being excluded from public school for her behavior. The student, Bridget, initially expressed concern over how the girl, Christine, was being treated and that her role as a one-to-one instructional assistant might act as a means of segregating her. Using the text analysis framework, she began by describing how the classroom teacher often referred to Christine as being “hard to look at,” even showing her an old childhood photo taken prior to cleft palate surgery. Bridget interpreted this as a process of “objectifying” and “closing off power” to the girl, allowing the teacher to “disconnect from her.” She also described how the Christine’s competence was undermined by reducing instruction to functional rather than academic skills, and by assigning her a one-to-one assistant. She wrote, “From an analytic perspective, the message being sent was that Christine would never be able to function without stringent guidance....The issue not being discussed is the fact that the problem wasn’t with Christine, but rather with Ms. Smith’s being unable to reach a student with her teaching methods.” Christine was eventually hospitalized, upon which Bridget reflected:

“Looking back on my experience, I realize that I was being used as a means to an end... I often wonder why I did not pursue an administrator about what was happening in this situation. I did not speak out because of my lack of experience. The teacher had a plan that was supported by other teachers, instructional assistants and district level special education directors. I honestly thought this was common practice... I have learned that if something doesn’t feel right, it probably isn’t. I was intimidated by titles of people and allowed that to influence my decision not to speak out.”

In the process of conducting a text analysis, this student identified how her actions were oppressed or shaped by power relations. Having a framework to move beyond personal criticism of this teacher, as well as of herself, allowed her to see injustice in its complexity and cultivate a determination for change.

## Conclusion

The opportunity to examine a range of responses to disability studies brings to light the influence of context on students' learning. Students' identities and positions in relation to traditional norms influence their understanding. More specifically, students who are heavily positioned in a positivist framework are likely to translate new concepts into notions of objectivity, personal blame and individualism. Their engagement is also influenced by the extent to which they are involved in disability studies, whether through a discipline specific program or singular course. With increased awareness of the possibilities and challenges of disability studies pedagogy, we hope, in the future, to create contexts which better engage students' dissonance and strengthen opportunities for transformation.

In situations in which there is a short time frame and strong dissonance, students will benefit from a directive approach in which heavy content can act as a frame of reference for critiquing positivist notions and constant reframing of the personal to the social. This is combined with providing students space and an opening to develop criticality as it is meaningful to them, around issues that are a source of connection, not strong sources of dissonance or threat. This is most likely to occur through links with gender, race, ethnicity or other sources of oppression with which they may have experience. The program situated initiative provides enhanced opportunities for both understanding the construction of oppression within a social system, in this case education, and for acting to change it. Whether in a stand-alone course or

program of study, we embrace combining critique with opportunities for action.

Disability studies represents an opportunity to address oppression from one of its main sources – higher education and institutionalized knowledge. While it is a significant struggle to counter dominant notions of disability and to raise injustice to the realm of social responsibility, the initiatives described in this paper demonstrate the possibility for change. Some students gained the determination to improve social systems, such as segregated education. Others took action, such as challenging a friend's use of derogatory language and questioning a landlord about accessibility. Learning what it takes to support and further this movement is a process of empowerment for all.

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# Disability in the Far East:

## Japan's Social Transformation in Perceptions of People with Disabilities

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**Abstract:** The phenomenon of disability is socially constructed; therefore, it is not free from norms, rules, shared understandings or value systems—in short, culture. This paper examines the universal presence of disability in the Japanese context, which is affected by a myriad of ever-changing influences, including political, cultural, and social forces.

**Key Words:** Japan, culture, disability

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### Introduction

The phenomenon of disability is socially constructed; therefore, it is not free from norms, rules, shared understandings or value systems—in short, culture. Cultural anthropologists thus argue that “all human societies have and have always had disabled members. While the presence of such individuals is constant, culturally shared responses to them vary greatly across time and social context” (Scheer & Groce, 1988, p. 23). This paper examines the universal presence of disability in a Japanese context, which is affected by a myriad of ever-changing influences, such as political, cultural, and social forces. Given that some readers of this article may not be familiar with Japanese culture, it seems appropriate to describe the cultural characteristics and political inclinations of Japan and their implications for disability.

### Culture and Disability

The ethnic homogeneity of Japan appears to trickle down to interactions with and perceptions toward disability. It is well known in com-

munication studies that the more homogeneous a society, the more culturally “tight” and collectivistic the members become (Triandis, 1994). This has many ramifications for how and why people interact as they do with each other. In a culturally tight society, which tends to develop in a highly populated and isolated geographic region like Japan, strict rules, norms, or ideas of proper behavior are imposed. In other words, a slight deviation from the norms is quickly noticed and criticized in a tight society. In such a culture, the force of conformity is stronger than in a loose one, and people are inclined to become more collectivistic, longing for “sameness” and loathing anything ambiguous, contradictory, or different (Triandis, 2003). Disability, however, is nothing but ambiguous,<sup>1</sup> contradictory,<sup>2</sup> and different. The sense of being tight and collectivistic has been an undercurrent in Japanese society, and communication regarding disability is rigid and tense.

Despite this undercurrent, Japan has experienced critical events concerning disability and people with disabilities (PWDs). The present paper contextualizes the social transformation of Japan through its policies, the media, and current demographic challenges, all of which have interacted within the environment surrounding PWDs.

### Policy Making

#### Equality of Access and Equality of Results

Heyer (1999) suggests that the notion of “equality” is interpreted quite differently in different countries, and these differences are deeply embedded in disability-related policies and legislation. According to Heyer, Japan employs an

“equality of result” doctrine, which acknowledges differences (and often disadvantages) resulting from impairments, and provides special treatments as compensation. Other nations such as the United States, interpret “equality” as securing the same access and treatment regardless of physical differences, as exemplified by the Americans with Disability Act.

“[W]hen does treating people differently emphasize their differences and stigmatize or hinder them on that basis? And when does treating people the same become insensitive to their difference and likely to stigmatize or hinder them on *that* basis?” (Minow, 1990; cited in Heyer [1999]; emphasis in original)

In answering these questions about the “dilemma of difference,” Japan has created difference-based disability policies from a welfare perspective, exemplified by disability employment quota, special schools, or taxi discount tickets. With the goal of special treatment and consideration, the Japanese welfare model of disability has created different spheres of living, especially in educational environments, which render disability invisible in society (Heyer, 1999; Iwakuma, 2005; Nakajima, 2006). Thus, the disability movement in Japan began with a counteraction against the conventional notion of disability (i.e., to be subdued or separated from the rest of society). The following section outlines Japanese disability movements, which began in the 1960s.

#### **A Brief History of the Disability Movements: The 1960s, 1970s, and 1980s**

It is generally accepted that the modern disability movement in Japan intensified and came into maturity in the late 1960s,<sup>3</sup> propelled by a group of people with cerebral palsy whose disabilities were most severe and who were deprived of social participation (Kuramoto, 1999; Tateiwa, 1997). Their group Aoi Shiba (“Green Grass”) formed officially in 1957, initially for recreation, but its purpose changed drastically

through several critical events that were considered by some to be antisocial or antagonistic (Hayashi, 2001; Kuramoto, 1999). One of these incidents was triggered in 1970 when a child with a severe disability was killed by her own mother. Subsequently, petitions were circulated to reduce the mother’s sentence, pleading that the mother was in such desperate circumstances in raising the pitiful child that the killing was done out of mercy and was thus understandable (Hayashi, 2001; Tateiwa, 1997). Aoi Shiba reacted angrily toward this “common sense” opinion that life with disability was worthless and was better ended, and they ran a counter-petition campaign against the mother.

Another famous turning point was the so-called “Kawasaki Bus Toso” (the Kawasaki Bus Strife). In 1977, members of Aoi Shiba stopped 78 city buses in Kawasaki that had refused to transport passengers using wheelchairs. Aoi Shiba members occupied and lay on the ground in front of buses to protest the denial of transportation of PWDs. Their antagonistic protest was disdained, both by non-disabled people and PWDs themselves, because Aoi Shiba members refused to apologize or plead (Tateiwa, 1997), as the “tight” and collectivistic society expected of them (Iwakuma, 2005).

Japanese culture prefers rigid and predictable social roles to avoid embarrassing scenes that can arise from unscripted interactions. Society expects PWDs, who are protected and supported by the state, to be conscious of the burden they impose on society and try to reduce it (Iwakuma, 2005). The cost of people with disabilities to society is generally thought to outweigh their contributions (Nakajima, 2006). During the Kawasaki Bus Strife, protesters decided to become an annoyance and burden by bringing bus transportation to a halt. Their defiance of an expectation imposed on PWDs was an eye-opener for others with disabilities; PWDs began to think outside of an inflexible frame, thereby changing the course of the disability movement in Japan (Kuramoto, 1999). This incident was

symbolic, because the issue of accessibility has played a central role in disability movements in Japan (and elsewhere in the world); securing accessible transportation directly translates into social participation for PWDs.

In Japan, accessibility for people with physical disabilities in the 1970s was incomparable to the current situation. For example, the number of passengers with wheelchairs at Tokyo Station in all of 1973 (the busiest train/subway station in the nation) was only 249 (Baba, 2004).<sup>4</sup> This low number illustrates that mobility for a person with a disability was quite limited in the 1970s and was met with many obstacles.<sup>5</sup>

In 1973, two stations, in Sendai and in Ueno, were remodeled for wheelchair accessibility for the first time in Japan; a ticket gate was widened and two bathrooms were made accessible (Baba, 2004). However, most stations remained inaccessible due to steps, a large difference in elevation between the platform and the carrier, or absence of accessible bathrooms. When Aoi Shiba members demanded accessibility at stations, officials were caught off-guard; they had never imagined that people with mobility impairments might even consider riding on trains (Nakajima, 2006). Thus, “obstacles” include not only physical barriers, but also society’s perceptions.

Imrie (2001) contends that “the socio-spatial patterns of ableist values are etched across the city in numerous ways, forming a type of architectural *apartheid*” (p. 232; emphasis in original). The ableism, according to Imrie (1996), is crystallized in the “denial of bodily diversity and differences and the projection of normalcy” (p. 83), and will be revisited later in this paper. A structure of specialities eloquently reveals the position of Japanese PWDs in the 1970s who were isolated and marginalized due to a different living sphere created by inaccessible environments.

The 1980s brought about many changes, including The United Nations’ International Year

of Disabled Persons in 1981 and A Decade of Disabled Persons, both of which facilitated disability movements that had arisen earlier (Tanaka, 1998). Yukiko Nakanishi, who has long been a part of the Japanese disability movement and travels throughout the world, commented to me at a recent meeting that she first started noticing “a shift in the wind” in the disability context during the 1980s. She further suggested that tenacious protests organized by groups of PWDs have had a lasting impact on policy and environmental changes. For example, members of Disabled Peoples International (DPI) have staged demonstrations, and in one such instance, more than 2,000 PWDs gathered at 20 different “inaccessible” train stations on the same day to use trains (Nakanishi, 2004). The continuous efforts made by the disabled have resulted in the establishment of guidelines for elevator and escalator installations at stations and the enactment of two laws: the Act on Buildings Accessible and Usable for the Elderly and Physically Disabled in 1994 and the Law for Promoting the Improvement of Public Transportation in 2000 (Nakanishi, 2004).

### Policy Making in the Disability Environment

Although “guidelines and outlines” for developers and architects of environmental designs for PWDs were established in the 1970s and approved by the government, the standards of that era were viewed as too generous. Therefore, architects and developers did not adhere to these governmental recommendations (Akiyama et al., 2001).

In the 1980s, environments for PWDs were drastically transformed, especially in the areas of community living and policy making, largely due to the United Nations-implemented International Year of Disabled Persons in 1981, and later, A Decade of Disabled Persons, from 1983 to 1992 (Tateiwa, 1997; Hayashi, 2001).<sup>6</sup> Many guidelines, projects, or plans were initiated concerning environments for PWDs such as housing, transportation, and employment (Tanaka, 1998).

A paradigm shift from a mere “recommendation” to “law” occurred in the 1990s. During this decade, public awareness of the issue of accessibility had become apparent. For example, 51% of those surveyed acknowledged accessible transit facilities inside stations for PWDs, and more than 80% believed that access was not sufficient for individuals with disabilities (Date et al., 1999). This trend went hand in hand with a cultivated public awareness that an aging society like Japan, which has the highest average life expectancy in the world (79 years old for men and 85 years old for women in 2008), cannot survive unless it becomes disability-friendly (Higuchi, 1997).

With this social background, two laws concerning accessibility were passed: the Act on Buildings Accessible and Usable for the Elderly and Physically Disabled (Accessible and Usable Building Law) in 1994; and the Law for Promoting the Improvement of Public Transportation (Transportation Accessibility Improvement Law) in 2000. Tanaka (1998) states that in the early 1980s, welfare laws predominantly targeted PWDs, but since the late 1980s, laws have been passed in response to concerns for the aging in Japan. This expansion or inclusiveness in the philosophy of accessibility, “access made only for the disabled” to “access for all,” was incorporated in the enactment of the New Barrier-free Law in 2006, which included the provision of accessible environments for all members of society.

### **The Media and Disability**

Circumstances surrounding people with disabilities in Japan seem to have changed in unexpected ways in the 1990s.

#### **Ototake: The Gotai-Fumanzoku Phenomenon**

In 1998, Ototake (1998) published an autobiographical essay as a person born without limbs; the book became an overnight bestseller and has been translated into many languages.<sup>7</sup> As more than five million copies of the book

were sold, media coverage of Ototake was intense and he became a social phenomenon (Iwakuma, 2002). His media appearances were welcomed enthusiastically. Unlike other people with disabilities previously seen in the media, Ototake rarely complained about having a disability or nagged the unaccommodating society, which put people at ease (Sakurada & Kohama, 2001). Throughout his life, Ototake was educated in mainstream schools and he graduated from a prestigious university. He has lived as a member of the able-bodied society, and his humorous comments contrasted with the conventional depressing, pitiful, and/or too sensitive images of others with disabilities. Many also pointed out that his handsome, well-groomed appearance has helped him gain acceptance. Upon university graduation, he chose to be a sports writer, got married, and more recently, became an elementary school teacher in Tokyo. The disabled and non-disabled communities perceived Ototake very differently (Iwakuma, 2002), and coverage of his life seemed to diverge from the traditional depiction of disability that is confined to a welfare or medical context.<sup>8</sup> I have heard from many individuals with disabilities who experienced social as well as interpersonal changes because of Ototake; for example, his book was often used as an icebreaker in conversations between people with and without disabilities. Talking about disability tends to be anxiety-filled, especially in conversations with a PWD (Iwakuma, 2002; Iwakuma, 2003); nevertheless, one of Ototake’s contributions has been to reduce the difficulty of these conversations.

#### **Nagano Paralympics**

Another significant event in 1998 was that the city of Nagano hosted the Winter Olympics and Paralympics. More than 500 athletes with disabilities from 32 different countries and regions flew into Japan. According to Takahashi (n.d.), who is an editorial writer for the Asahi Newspaper, this event was noteworthy in several aspects compared to previous Paralympics. Despite the relatively high cost of tickets, they were

sold out within a week immediately following the opening ceremony (Nebashi & Inoue, 2005). The mass media enthusiastically reported not only game results but also personal stories of the athletes. The Asahi Newspaper, one of the major nationally-circulated papers in Japan, reported the four medals won by Mayumi Narita in color on the front page, but also published a feature article about her ([http://www.yuki-enishi.com/media\\_shougai/media\\_shougai-04.html](http://www.yuki-enishi.com/media_shougai/media_shougai-04.html)). Other articles about the Paralympics appeared in the sports section instead of the lifestyle or health sections of the newspaper (Nebashi & Inoue, 2005). More than 10,000 people per day visited the official Paralympics website during the games, and many people with disabilities were inspired and became interested in these sports (Nebashi & Inoue, 2005). In the Asahi Newspaper, two short articles about the Paralympics appeared in 1988, three in 1992, and only one in 1994; however, the number of articles about the Nagano Paralympics exceeded 100 in 1998. Furthermore, disabled athletes' names were given without any title, such as 'Mr.,' which is the same convention used for reporting the names of non-disabled athletes (Takahashi, n.d.).

The Nagano Paralympics has left long-lasting effects on the perception of disability in Japan. During these games, people in Japan were exposed to new images of competitive and accomplished athletes with disabilities, in stark contrast to the conventional "depressive, frail, unathletic, and/or immobile" perceptions of PWDs (Iwakuma, 2004). At the same time, the media made it apparent how ablest the environments were for individuals with disabilities. The present author saw footage of a non-Japanese athlete in a wheelchair who visited a local Japanese souvenir store. To traverse the several steps at the entrance, which are typical for small stores, the athlete stepped off the chair and crawled up the stairs, before an astonished store owner came to rescue him. By watching Paralympics athletes with various kinds of disabilities, Japanese people came to the realization that there was a group of people, the so-called

"disabled," who were often forgotten and subdued due to different living spheres created by society (Takahagi, 2000).

## Changing Japanese Society in the 1990s and Beyond

### The Great Hanshin/Awaji Earthquake

On January 17 1995, the Great Hanshin/Awaji Earthquake shook the nation. More than 5,000 lives were lost, many of them elderly people over 60 years old (Tanaka, 1998). Major infrastructures were cut off in the aftermath, and the nation, standing on shaky ground, witnessed how conditions normally taken for granted (e.g., water, electricity, roads) were changed. Many people regarded as "able bodied" under normal circumstances suddenly underwent experiences common to people with disabilities. For example, many disaster victims were isolated from the flow of information, could not use the toilet or bathe for days, or were unable to go to school or work (Kawauchi, 2001). In addition, temporary houses contained many barriers, and receiving food or water outside on the street in cold January added another difficulty for PWDs and the elderly. Removed from a familiar community network, many disaster victims died from despair and isolation, demonstrating the importance of a social network for survival.

This experience has provided many valuable lessons for the rest of the country regarding city planning, transportation, and living environment (re)creation. As the revitalization of Hanshin proceeded in tandem with responses to needs of the aging, issues such as accessibility, barrier-free environments, and universal design became well known to the public. Following this earthquake, tangible changes took place throughout the nation due to the understanding that this could happen anywhere in Japan (Kose, 2002; Tanaka, 1998). For example, the rebuilt Itami station and its surrounding area were designed to be barrier-free. Many stakeholders comprised committees and provided

ideas prior to the design phase and evaluated the newly built station areas afterwards.

Another change was seen in housing. Prior to 1995, a step at the bathroom entrance was considered necessary in Japanese housing to prevent water from flowing outside the area.<sup>9</sup> When a large number of people, many of whom were elderly, lost their houses and moved to public assisted apartments after the earthquake, the state put a great effort into creating step-free bathrooms (Kose, 2002). This action took place due to the provision that the residents would remain in the apartment for the rest of their lives and was based on concerns about future remodeling if the bathrooms were not made accessible initially (Kose, 2002). Mass production of step-free bathrooms has become a norm in Japan, even beyond earthquake-prone regions (Kose, 2002).

### **The Low Fertility Rate, Demographic Change and Its Implications**

Another prominent factor in the changing contexts surrounding disability and accessibility is Japan's aging society, in tandem with the ever-shrinking fertility rate. Kose (2002) states that prior to passing the Accessible and Usable Building Law, the Building Standards Law was passed more than 40 years prior when the elderly comprised only 5% of the population, average life expectancy was approximately 50 years, and PWDs were rarely seen in public. Therefore, it is not surprising that pedestrian overpasses without elevators, overcrowded trains, flights of stairs at stations, and city buses with steps were all designed for the "normal" body with upright posture, walking, healthy, and strong. This narrow standard of the human body that negates bodily diversity and capacity is referred to as *ableism* (Imrie, 1996). However, the burgeoning demographic shift has changed societal views—ideas about accessibility have shifted from benevolent facilities designed for the disabled only to an environment in which the entire aging population may live in coming

years (Nomura, Hagisu, Sugiyama, Nozawa, & Hatougo, 2005; Tanaka, 1998).

With the establishment of the Dwelling Design Guidelines for the Ageing Society in 1995, the housing industry has become more conscious of the needs of the aging population (Kose, 2002). Within the state government, newly employed Ministry of Construction bureaucrats now receive training that includes simulated experiences of mobility impairments by the wearing of braces or casts (Kose, 2002). Another area seriously affected by aging is tourism. For example, the city of Kyoto is one of the oldest cities and boasts a long list of nationally renowned sites or architectures, many of which are filled with barriers such as stairs or pebble-filled paths. Due to these physical obstacles, an untold number of elders and PWDs have given up visiting and worshipping at temples or shrines. However, aging baby boomers possess purchasing power and an abundance of time after retirement. Thus, the Kyoto tourism industry is prioritizing barrier-free or universal design. In 2000, 15.1% (611 million people) of all visitors to Kyoto were over 60 years of age, and this number increased to 17.4% (822 million) in 2005 ("Yasasii kyo no tabi," 2006). Thus, under the tide of aging, the ableist landscape begins to be considered not only socially unjust but also economically unsound.

Nomura et al. (2005) reported that the barrier-free movement started originally to improve the lives of PWDs, and later included the elderly due to Japan's aging society, and more recently has included child-rearing parent(s). Parents (especially mothers of small children) have joined the alliance under the slogan of "barrier-free for parenting" (<http://www.yomiuri.co.jp/iryoku/kyousei/geneki/20050803ik08.htm?from=goo>).

In 1989, the government report of Japan's fertility rate of 1.57, which was subsequently called "the 1.57 shock", stunned the nation. The fertility rate has not recovered, and in 2005, for the first time since the first national census of

1899, in the absence of an external factor such as a war, the Japanese population decreased.

While many reasons are suspected for the lowering fertility rate (e.g., diversified women's lifestyles and their increased participation in the workplace, high cost of education, or shortage of childcare facilities), negative perceptions and child rearing experiences in ableist environments have been acknowledged as contributing factors. When the city of Tokyo asked for public comments for improvements to the environment, more than 3,000 comments were sent in. Many of them raised concerns about current environments that are unwelcoming for many people, including child-rearing parents. More importantly, these comments pointed out that "barrier-full" environments discourage people, especially women, from having children, and this trend further reduces the overall fertility rate ("Tokyo koso," 2000). For example, a poll shows that although more than 95% of surveyed mothers wish to go out, the majority has become nearly housebound and feels distressed as a result ("Hirogare," 2007). With a small child, parents (especially mothers) are aware of their communities from a different perspective and often are astounded by the existing obstacles. A mother with small children, one of whom is eight months old, reveals that she becomes very nervous about anticipated barriers before leaving home (<http://www.yomiuri.co.jp/iryoku/kyousei/geneki/20050803ik08.htm?from=goo>). For example, a stroller is generally expected to be folded on the bus,<sup>10</sup> and in stations without elevators, the stroller must be carried up and down stairs with the baby inside.

Connecting the dots between living in a "barrier-full" society, the added or perceived parenting stress, and reluctance to have a child, the Japanese government has begun promoting the slogan, "barrier-free for parenting". Accordingly, a white paper published in 2005 was devoted to the issue of low birth rate and acknowledged the environmental factor on the dwindling births, reflecting that conventional, ableist

living arrangements have undermined "other bodily configurations," including child-rearing parents, the elderly, and people with disabilities ("Shoshika hakusho," 2005).

### The 3.11 Shock and Beyond

"It's been enough." This was the last phrase Masaaki Sato gasped under a respirator when the Magnitude 9 earthquake hit and nearby family members were scrambling in an effort to rescue Masaaki (Kirikuri, 2011). The tsunami was about to wash everything away, including PWDs with limited mobility like Masaaki. The Great East Japan Earthquake took place on March 11, 2011, and Japan has been plagued with aftershocks ever since. This section details the survival experiences of PWDs in the earthquake aftermath in three consecutive stages.

In August 2011, the author interviewed Awano, who works at a community workshop for PWDs and has visited quake-affected regions. Awano mentioned that a person with severe disabilities faces three hardships when and after a disaster hits (JDF, 2011). The first stage is when the disaster hits—those with severe mobility impairment simply cannot escape on their own, as was the case for Masaaki Sato.

A PWD also faces difficulties in the second stage—at evacuation centers. Such centers, which include school gyms and community centers, are not an option for PWDs due to physical and psychological barriers. Awano, who visited many shelters, came to realize that very few PWDs stayed at evacuation centers in which survivors, with or without disabilities, slept on floors, and bathrooms and toilets have steps with little privacy. One party of 24 (4 staff and 20 people with psychological disabilities) was turned away from a shelter (Awano, personal communication, August 18, 2011). At least four individuals with psychological disabilities died after surviving the earthquake and tsunami (Nokura, 2011), and this number increases as the situation prolongs. In particular, the drastic changes in living environment can

trigger seizures and/or worsen preexisted health conditions in some PWDs. For the majority of PWDs, evacuation shelters are inhabitable, and many have no choice but to return to their unsafe homes or stay with relatives (Awano, personal communication, August 18, 2011). Since relief supplies only arrive at evacuation centers, PWDs that decided not to stay at such centers were “out of sight, out of reach,” according to Awano.

Two months after the earthquake in May 2011, Miyagi prefecture reported that 15 PWDs died and seven were missing, despite the fact that there were more than 50,000 registered PWDs in the prefecture (Kyouzaren, 2011). This blatant underestimation may be attributed to the new Private Information Protective Law, which was passed in 2003. Under this law, the whereabouts of PWDs must be concealed, contributing to the notion that the law presents an additional obstacle for confirming the safety of these individuals. The handling of private information during crises requires careful reconsideration.

The third stage begins when survivors move into temporary houses and start rebuilding from scratch (Awano, personal communication, August 18, 2011; JDF, 2011). During an academic conference, which the author attended in August 2011, issues concerning the third stage were frequently mentioned and debated. For example, a conference attendee with a disability commented that newly-built temporary houses were small, built in remote areas, and uninhabitable for many PWDs. In response, a researcher involved with the housing project replied in an apologetic tone that a massive number of temporary houses had to be built in a short time frame (i.e., a few months); therefore, the issue of “barrier-free” had been compromised. He added that although the bathrooms were designed with thresholds, the toilets had no steps. This was the aforementioned lesson learned from the Great Hanshin-Awaji Earthquake in 1995. Another bitter lesson from the previous earthquake

was that during the third stage, tight-knitted communities were broken up and some survivors died in solitude while living in temporary housing (Tanaka, 1998). Not to repeat the same mistake efforts were made to have communities stay and move together to temporary shelters when possible.

Since the 3.11 earthquake, Japan has never been the same. While no person was untouched by the incident, people with disabilities seem to have been affected the most drastically.

### Concluding Remarks

The current paper details Japanese disability contexts that have been in constant flux between the universality of disability and fluidity of disability terrain. While the cultural or political tendency of being “tight and collectivistic” and the “equal result” policy set a tone in disability environments, critical incidents noted in this article have drastically transformed circumstances for PWDs. Some events were international (the United Nation’s International Year of the Disabled Person and the Nagano Paralympics Games), while others domestic (the Great Hanshin/Awaji Earthquake, low fertility rate, and the Gotai-fumanzoku phenomenon), and all seemed to have affected the public perception of PWDs and accessibility. Aoi Shiba should not be forgotten, because their struggles and demonstrations in the 1960s opened the door for the Japanese disability movement and left a significant mark.

Ableist living environments, with narrow definitions of “normalcy,” seem to have worked well in Japan’s “tight and collectivistic” society, which strictly dictates orderliness and stresses efficiency. After all, from an economic standpoint, it was the strict standardization and like-mindedness that resulted in the success of the Japanese economy (Nakajima, 2006). However, this was accomplished at the great expense of compromising diversity, including opinions and bodily configurations; that is, both in the able-

ism and like-mindedness (or “tight and collectivistic,” to borrow terms from communication studies), diversity is interpreted as “noise” that undermines efficiency and the status quo.

Nevertheless, since the 1980s, ableism has been seriously challenged by, for example, the demographic shift, accompanied by the declining birthrate and burgeoning older population. Aoi Shiba’s protests of the 1960s and 1970s against the spatial architectural apartheid based on ableism is socially warranted today, as more people with or without disability have joined the barrier-free movement. Moreover, the movement in Japan has a spill-over effect especially in other Asian regions because the nation hosts people with disabilities from other countries for leadership programs and international networking (Ohtsuka, 2004).

In the end, it is this author’s hope that more cross-national/cultural disability studies will follow wherein unique challenges as well as common disability experiences are shared and discussed.

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## Endnotes

<sup>1</sup> Murphy’s (1990) notion of liminality accounts for the ambiguous social role of people with disabilities caught in a transitional state between healthy and sick, which results in a social limbo status.

<sup>2</sup> Both the non-disabled and people with disabilities feel the contradiction. Contradictory messages surrounding disability, such as “help the handicap” and “treat the disabled just like anyone else,” leave the non-disabled feeling tense, ambiguous, or uncertain about interacting with a person with a disability (Braithwaite & Braithwaite, 2003). Nakajima (2006) states that the aforementioned intrapersonal conflict creates a barrier when communicating with a person with a disability.

<sup>3</sup> According to Sugino (1993), around the turn of the 20<sup>th</sup> century, a group of people with visual impairments first mobilized a political campaign, the so-called blind movement. This movement originated from the need for employment security, which was bolstered by a vertical, master-apprentice occupational relationship; at the same time, this occurrence laid the groundwork for

a horizontal, collegial consciousness among people with visual impairments (Sugino, 1993).

<sup>4</sup> In 1999, ridership at Tokyo Station was 30,174 per year and 2,514 per month.

<sup>5</sup> In 2000, the long-awaited Oedo line began operating a forty-kilometer loop railway circling outside of the Imperial Palace in the heart of Tokyo. This railway system was built to embody the philosophies of “access for all” and the Transportation Accessibility Improvement Law. Eight months after its opening, more than 1700 wheelchair users were using the line every month and about 34 per 10,000 users are people using wheelchairs (“Oedo-sen,” 2001). More importantly, the Ministry of Land, Infrastructure and Transport reports that the opening of the Oedo line has not only improved lives of PWDs in general, but also stimulated consumer activities of the elderly and PWDs; increased transportation means employment, a decreased burden on family members and station employees, and changed mind-set of PWDs (“Oedo-sen,” 2001).

<sup>6</sup> Ripple effects of these implementations by the UN seemed to have been felt in other world regions. The German Disability Movement was born at this time (Kobsell, 2006).

<sup>7</sup> The English title of this book is *No One Is Perfect*.

<sup>8</sup> Within a communication framework, Iwakuma (2003) discusses circumstances surrounding the Ototake phenomenon.

<sup>9</sup> In Japan, people wash outside of the bathtub.

<sup>10</sup> This “folding stroller” regulation has been changing, and increasingly in recent years, public transportation, such as buses and trains, allows unfolded strollers (“Hirogare,” 2007).

# Paulo Freire, Disability, and Sociological Consciousness in a Southern Metropolis: The Knoxville Mayor's Council on Disability Issues

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**Abstract:** This article examines attitudes and opinions among members of the Mayor's Council on Disability Issues (CODI) of Knoxville, Tennessee. Using focused interviews, respondent commentary is presented on topics such as the disability rights movement, employment and education, the nature of defining disability, and the functionality and relative importance of CODI as a whole. Paulo Freire's (1968) model of oppression is used as a frame of reference to examine CODI members' attitudinal assumptions of these issues.

**Key Words:** government, social change, Freire

## Purpose and Overview

This study examines the disability-related power structure in a city government as a means for effecting social change in a local community. My case is the City of Knoxville's Mayor's Council on Disability Issues (CODI). CODI is a mayoral advisory and consultative group consisting of 21 individuals, who are committed to a community focused on the full integration of individuals with disabilities. The bylaws mandate that at least half of this body be individuals who are disabled. Members are lay experts in the community; some disabled themselves, while others have close relationships to people with disabilities.

This case study is purely exploratory. Its purpose is to gain insight and information, as well as to posit questions that may be worthy of more systematic and comparative study. What can we learn from this group of activists who, as CODI members, necessarily operate in an administrative context? The study explores the CODI's influence on public policy in the city

of Knoxville. The exploration reveals new politics of disability in an era—our era—that lacks a significant national disability rights movement.

Of course, one of the most frequently debated issues among political activist organizations is whether to effect change from within or outside of the organization's own bureaucracy. CODI is unique in that it is both within the city government, purportedly having the ear of the mayor, but also outside of the government because the council members hold no real authority or power. It could be said that CODI exists as a liminal construct—it exists in a space between the city power structure and the oppressed, the disability community.

But what exactly constitutes “oppression?” Paulo Freire (1968) presents a useful analysis of oppression, which grows from and is meant to encourage liberating non-violent social change. From his perspective, an individual must become aware and desire *change*. This awareness of oppression and want of change is accomplished by an education that is not based on the teacher/student dichotomy (wherein students are empty “banks” waiting for teachers to “deposit” knowledge), but rather on an equal exchange of ideas. Once this consciousness is achieved, an individual may critique society in order to enact social change. Freire reiterates that one should never accept oppression.

Interview responses from CODI members are compared with Freire's model of oppression, oftentimes mirroring similar, if not identical, themes in respondents' own notions of *disability*-related oppression. Using this model, I posit that people who live with disabilities in American society are easily identified as an oppressed people. Specific examples of the re-

spondents will provide illumination into Freire's basic paradigm of oppression. One cannot simply receive disability awareness training like any other paternalistic "banking" pedagogy; rather, they must actively engage with individuals who have disabilities in order to achieve true "disability awareness education." In addition, Freire's framework of education for critical consciousness, explained below, translates well into respondents' notion of integrating disability information into both public awareness projects and school-related curricula.

### Study Design and Execution

This study utilizes a mixed-methods approach, based primarily on participant observation and focused interviews of an intentionally non-random group. In addition, a brief quantitative survey was administered for basic, descriptive statistics. The group studied was the 21 members of the Mayor's Council of Disability Issues (CODI) in Knoxville, Tennessee. The goal was to produce a reasonably detailed description; including their knowledge about disability, their consciousness about CODI's efficacy in influencing city policy regarding disability issues, their thoughts about whether CODI is taken seriously by the mayor and city council, and their views concerning whether the disability community is an "oppressed" and/or "disadvantaged" minority group.

Council members represent many different organizations in Knoxville, Tennessee. These include: SunTrust Bank, Elavon (a payment corporation which promotes a diverse workplace, including people with disabilities), the University of Tennessee, the Center on Disability and Employment, Disability Resource Center, Peninsula Hospital, Value Options (a counseling corporation), Breakthrough Corporation (a non-profit organization for adults with autism), Tennessee School for the Deaf, Goodwill Industries, Patricia Neal Rehabilitation Center, and the Disability Law and Advocacy Center. Some work in fields directly relating to disability, while

others are employed either as university faculty/staff or as recruiters for private companies.

Although my hope was to elicit 100% participation, three CODI members were unable to participate in the study. An additional two were also omitted due to their prior knowledge of the project and their roles in its planning. These two individuals instead served as informants. These informants' roles were multifaceted and included helping me to determine what questions would elicit the most fruitful responses in interviews, and appropriate and inappropriate means for approaching sensitive questions about one's personal disability. These "informants" also reviewed and revised the survey instrument. Therefore, in the end, a total of 16 of 21 were interviewed, a response rate of 76%.

I adapted methods for valid and reliable interviewing from *Researching Social Life* (Gilbert, 1993; Gilbert, 2008), a guidebook ideal for any social science researcher, but especially for those just starting out at the undergraduate level because it utilizes a very clear, parsimonious, and stylistically accessible language for learning methodological techniques. Interviews lasted approximately 60-90 minutes. All interviews were recorded and partially transcribed to extract meaningful themes. Confidentiality was assured to every participant, although each gave permission to have his or her statements quoted. Interview questions were open-ended and centered on the following succession of interrogatives: What is your personal, individual experience with disability? Why are you on CODI? What do you think is the purpose of CODI? How does disability relate to oppression?

The first question was used as a determinant to gain insight into the respondent's perspective. From this question, respondents could be easily divided into two basic categories—those who themselves have a disability and those who do not but have a relationship to an individual(s) with a disability. Each conversation was pursued differently after the personal experience

with disability question, with the ultimate goal being to encourage the respondent's full elucidation of their particular perspective and experience.

The interview was followed by a written survey that had questions using a Likert scale. The survey was composed of 19 questions, including basic demographic questions. The purpose of the questionnaire was to provide data for tentative generalizations about the group. Unfortunately, this instrument proved largely unreliable because respondents either: (1) left questions blank or (2) crossed out portions of the questions, reworded them, and then proceeded to answer their own question.

The demographic data, however, provides this result. All but one member of CODI are white, all are well-educated (with half possessing a Master's or Doctorate), and most are older than 35. This racial and socioeconomic composition does not reflect the greater disabled community locally in Knoxville, or in America as a whole. Indeed, it is common wisdom that racial minorities and those living in poverty are the more likely to be disabled, frequently living with co-morbidities (e.g. Oliver & Muntaner, 2005).

The demographic data suggests that CODI is not a representative group of the local or national disability community. It is certainly a self-selecting group, open only to those nominated by their predecessors. This process tends to discourage membership from those not already possessing significant ties in the community. The voice of the "average" person with disability concerns, lacking the social connections and education necessary to be nominated to CODI, is perhaps too often, therefore, denied access to membership—although anyone can attend meetings and participate. So though diversity of board members may be suspect, one might mistakenly assume that people with disabilities in the community attend meetings, speak publicly, and make a contribution. Indeed, in the February, March, and April meetings, the room was

empty except for the board members and me. The importance of active participation cannot be overemphasized, as Freire (1968) reiterates: "Attempting to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects which must be saved from a burning building; it is to lead them into the populist pitfall and transform them into masses which can be manipulated" (p. 52).

## Responses

### Disability Rights, the Disability Community, and Non-Profit Organizations

The Disability Rights Movement was a topic discussed by all respondents in their individual interviews. Most expressed that this movement's progress culminated with the Americans with Disabilities Act of 1990, though respondents stated this provided only a minimum for accommodations. Nevertheless, they agreed that it was certainly a good starting point when it came to legislation. Some felt that the movement's accomplishments paled in comparison to those of other minority groups that lobby for equal rights. One respondent believed that what makes people with disabilities so unique from other minorities is their inherent difficulty in being politically active. Whereas oppressed groups, such as people of color or GLBT individuals are able to physically protest their oppression, the disability community is often constrained from doing so. People with visual impairments may have difficulty reading relevant legislation and news articles. Individuals with hearing impairments may have difficulty listening to radio broadcasts, lectures, or town meetings related to disability. Wheelchair users, as well as the visually and hearing impaired, have difficulty attending and participating in city council meetings, political protests, or rallies. People who are homebound due to their disability are hard-pressed to do any of the aforementioned activism. While some interviewees speculated that this may change with the Internet, accessible technologies (e.g., computer

programs with text-reading capabilities) remain expensive and, consequently, perhaps are not universally utilized by those who would benefit from this potential access to the public sphere.

Access to the system and the legislative process is inhibited, severely limiting the participation of those with disabilities even more so than those minorities who have no physical barriers to government. Freire's notion of a "... 'culture of silence' in which the oppressed or underprivileged are overwhelmed by the power of the dominant elite" (Sloop, 1987, p. 16), becomes especially useful when applied to this context. As mentioned in the interviews, people who have an "obvious and severe" disability have a particularly difficult time getting their voices heard in the vast "silence" that represents a supposedly democratic and transparent government. Existence, in the Freire sense, stems from political activism that arises from the knowledge that "... dehumanization through denial of political freedom is not just an ontological possibility but a tragic historical reality" (Collins, 1977, p. 64).

Going beyond *physical* disabilities, multiple respondents expressed dismay over people with intellectual or mental disabilities being completely kept out of decision-making affecting their own lives. One respondent reiterated an example:

"In particular someone who has a severe intellectual disability, such as a tested IQ of 35 and who has a lot of adaptive behavior deficits. They may not be able to speak up and advocate for themselves as much as a blind person, for example.... Our society, unfortunately, has a tendency to dismiss that person, to discount what they have to say, regardless of what they have to say."

Another respondent said, "Nothing about us without us," with reference to adequate representation, along the same lines as "No taxation without representation."

The internal state of the disability rights movement also became a pervasive theme in the interviews. All respondents thought that the movement lacked any significant cohesion or even a common goal. Frequently cited was the African-American community that, despite division, has shown much cohesion with regard to equality of opportunity in this country. People of color have deep-rooted foundations of community in their churches, neighborhoods, families and even historically black colleges (Moore, 1991; Dominguez & Watkins, 2003; Rankin & Quane, 2000). Individuals with disabilities do not have their own churches or their own neighborhoods (aside from care facilities and hospitals). When it comes to a family or household unit, there is often only one member who is disabled, if even that. This lack of unifying social institutions among people with disabilities makes community social support difficult, even if oppression is common to all these individuals. Perhaps this is due to a lack of movement leadership which one respondent brought up. She stated that the lack of a concerted effort was caused by having no visible spokesperson or charismatic leader to get behind. Indeed, for people with disabilities, there is no Harvey Milk, no Susan B. Anthony, and no Martin Luther King, Jr.

The overwhelming number of Knoxville's disability-specific organizations and foundations were also thought by many respondents as being deterrents to a unified social movement. Some CODI members also serve on boards for the multitude of these local disability foundations. A few local organizations include: The Epilepsy Foundation, Muscular Dystrophy Association, A Silicon Bullet for Dyslexia, Hearing and Speech Foundation, and Sertoma Center (a residential care facility for individuals with intellectual disabilities). A cursory glance at these organizations' promotional materials shows that they have similar, if not identical, goals. Chief among these is promoting awareness for a spe-

cific disability, as well as placement services for people with disabilities seeking employment. Some organizations, such as the Epilepsy Foundation, provide employment placement services for not only individuals with Epilepsy, but anyone who requests the service. Therefore, one may be tempted to ask the questions: Why even have these multiple organizations if they all do the same thing? Would it not be easier to consolidate them into one “Knoxville Disability Center” rather than having multiple independent organizations, each with funded offices, staff, and overhead? Respondents all agreed that in a perfect world this model would be ideal. In practicality, they stated, it would require the many executive directors and board members relinquish their control—an unlikely event.

### Employment and Education

Several members of the Mayor’s Council on Disability are involved in ensuring that people with disabilities can find gainful and accessible employment. Several respondents emphasized the importance of employment instead of government assistance; that to live on SSI benefits is detrimental to an individual’s mental and physical health. Mentally, stated a former government beneficiary, the danger lies in falling into feelings of worthlessness and self-loathing; physically, the poor healthcare benefits are problematic, and financial payments often fall below the poverty line. Freire (1968) makes a similar assertion about oppressed people that perseveres to the present day and in numerous contexts of minority groups, “So often do they hear that they are good for nothing, know nothing, and are incapable of learning anything—that they are sick, lazy, and unproductive—that in the end they become convinced of their own unfitness” (p. 49). This notion was mentioned by several respondents with comments such as, “*Society* has established that disabled people should not work.”

Some respondents believed that people with disabilities gained freedom through their equitable employment, rather than having few al-

ternatives but to live on government stipends. They stated that while employment may be a significant aspect of independent living, much of an individual’s quality of life comes from how they are perceived and their own self-perception. Freire agrees that “The oppressed are situated within an economic and social structure and tied to it not only by their labor but also by the conditions of their psychological being” (McLaren & Leonard, 1993, p. 17).

In contrast to the predominantly unitive opinions on employment, the topic of education generated a wide variety of comments. Some of the CODI members with a disability said that they experienced extreme discrimination in obtaining their degree(s), while others had little trouble. Interestingly enough, people on both sides of the argument graduated from the same local institutions, yet had vastly different experiences. Another concern mentioned by the participants related to the K-12 school system. There is no disability awareness in the local Knox County school curriculum, which seems to be the norm for many school systems nationally. I pose the question, then, as: Could disability awareness education from a young age bring forth a more disability-friendly tomorrow? The literature reflects the affirmative: “One of the most effective ways to shape people’s knowledge, values, and attitudes is through instruction—formal schooling, adult programs, classes and workshops...schools are so crucial in the socialization process” (Curry, Jiobu, & Schwirian, 2008, p. 499).

### Defining Disability

Another theme that emerged early on was the definition of disability. Respondents stated that everyone is disabled in one way or another. One individual went so far as to define that while everyone is disabled in doing any given thing, there are “obvious” disabilities such as blindness, deafness, cognitive dysfunction, and mobility problems. But, as one respondent stated, all disabilities are strictly relative. To use an example, one respondent stated that there

is nothing inherently wrong with someone's sight, except that they see less than everybody else sees. If we lived on a pitch-dark planet and had evolved from sight perception, it would be quite the norm to be blind. If an individual has a distinctly low IQ—low enough to inhibit daily communication, for example—then they are only less intelligent than everybody else. Normative value judgments play an enormous role in determining, upon first contact, who is a person with a disability and who is a so-called “normal” individual.

Many interviewees reiterated the fact that all of society is continually becoming more and more disabled. It is a rare instance for a fully functioning adult to die naturally with all five faculties intact, especially sight and hearing. As we age, our sight, hearing, mobility, and cognitive functioning oftentimes steadily decline as well. Thus, most of us will experience disability of some type during our lifetimes.

In defining disability, three participants brought up the concept of dependency. They posited that people with disabilities are seen as dependent on everybody else—their caregivers, the government, and society. The word *dependence* evoked resentment among a few members, favoring instead the word “interdependence” with its practical application in everyday society. Indeed, everyone is dependent on everybody else in order for any society to function on a daily basis. Even if one were to isolate him or herself from the world, they would still need others to produce their electricity, to bring them food, and to provide items they are incapable of making.

#### **Membership in the Mayor's Council on Disability Issues (CODI)**

Francisco Weffort writes in Freire's preface, “The awakening of critical consciousness leads the way to the expression of social discontents precisely because these discontents are real components of an oppressive situation” (Freire, 1968, p. 20). Critical consciousness, as men-

tioned in the introduction, means being aware of one's society in a realistic sense, acknowledging its shortcomings and, perhaps, noting the irony of a system that purportedly works well, but in reality oftentimes, overlooks the overall picture. Metaphorically speaking, seeing the forest and not the trees, though if there were no trees, there would be no forest. To some degree, CODI was created with this in mind, especially when you take into account that half of CODI's membership is mandated as people with disabilities, in this case, the oppressed or “social discontents.” Individuals who have lived in this society and experienced the dehumanization know firsthand and more intimately what needs to be changed. Therefore, CODI's membership composition is ideal if one desires social change.

CODI members expressed several opinions about their own membership. Thoughts ranged from the negative and bitter to the positive and visionary, favoring the former over the latter. Respondents were all asked if they believed that the mayor and city council took them seriously. Some declined to comment, stating that they could not read other people's minds, while many expressed their concern that the city government took them seriously only retroactively, not proactively. That is, when a policy or legislative item comes up on the agenda, CODI primarily acts in protest rather than prevention. When asked if CODI members attended any of the city council meetings, the response was a unanimous “no.” A handful admitted to going to public meetings of the city council when there was a hot issue that directly related to the disability community, but none saw it necessary to attend on a regular basis. One respondent made the suggestion that perhaps members of CODI could schedule a rotation such that at least one representative from the body could attend these meetings. Another believed that the body as a group should attend city council meetings, making their presence known. On the other hand, if a city council member were to attend a CODI meeting, then perhaps adminis-

trators would take the body more seriously. In the past three meetings that I have attended, I have been the only audience member in attendance.

Interestingly, the Council on Disability Issues inadvertently models itself on the Knoxville city government; it mimics the city government in *all* of its proceedings. CODI meets in the same physical chambers as does the city council and mayor, as well as utilizes parliamentary procedures, maintaining a bureaucratic infrastructure for discussion and record-keeping, and keeping a membership of individuals whom are all approved by the city council (as well as CODI incumbents). Freire (1968) writes that in any power structure, when the individuals who were once inferior are made superior, these individuals change. The once oppressed now become the oppressors, taking on the very role which they so despised in the first place. He calls this an “existential duality” wherein the oppressed are both themselves and “the oppressor whose image they have internalized” (p. 47). This explanation may shed light on loss of interest among CODI members, who perhaps initially joined the group with enthusiasm and the desire to affect social change, but after gaining official recognition, preferred to maintain good relations with the mayor and city council, rather than challenging the status quo. One might argue that CODI has become the very embodiment of bureaucracy and red tape which oppressed people with disabilities have come to despise.

Excessive board member absences seemed to be one attribute of CODI’s inactivity. Two individuals were adamant about the importance of attending meetings regularly. “If you can’t make the monthly meeting every 2nd Wednesday at 4:00, then why do you serve on the board?” A couple individuals suggested that people signed up more because of selfish, rather than selfless reasons. These included the “résumé value” or “pride factor” of people who are a part of an official mayoral body. At some point in CODI’s

history, excessive absence was so severe that for a period of 1-2 years not enough people would show up for the minimum quorum necessary to take a vote that would change the bylaws to allow for a smaller quorum. While absences related to work, family, and illness were understandable, it seems the same individuals skip meetings on a regular basis. This was a matter of frustration among those I interviewed who attended meetings religiously. Absenteeism also provides further evidence of Freire’s existential duality, which is to say that once you get the recognition of being an official board member, the hard part is over.

This brought up another theme—visibility in the community. The overwhelming majority of interviewees stated that “nobody knows about us” or that this council is virtually “non-existent” in the disability community of Knoxville. A few current council members even acknowledged that they had never heard of it and had no idea what it was until they were asked to serve on it. A need to develop this body’s reputation as a household name among individuals with disabilities was reiterated repeatedly in interviews. “More visible all the time, not just an angry mob when something happens” was a sentiment expressed by one respondent and reiterated by others. Another person thought that perhaps when CODI has not done anything of significance in awhile, the city council and mayor forgets about them. When asked if CODI has done anything significant in the past year, several respondents hesitated for a moment, but did come up with 2 “big ticket” items that they had done or were doing at present. However, a few stated that while historically CODI did much, currently the council’s activity had dwindled. One interviewee stated that the small 3-4 person committees within the body have done much in terms of activity in recent years and that having more designated committees to actually “do stuff” would allow the council to do more for the community, rather than trying to get the whole body to agree on specific items. This is especially evident in the tightly sched-

uled 60-minute monthly meetings at which motions are passed, guest speakers are heard, and complaints are voiced.

Many CODI members stressed the lack of visibility and disability awareness promotion as being major causes of continued discrimination and inequality among people who are disabled. Freire agrees that, beyond activist participation, consciousness-raising should be at the forefront of change. He states that it is "...the absolute necessity of the oppressed to take charge of their own liberation, including the revolutionary process which, in the first place, is educational" (as cited in McLaren, 1993, p. 16). Indeed, when asked what the purpose of CODI was, many respondents said that it was to bring awareness to those with power in the city, to help them see and understand the plight of the disabled community in Knoxville, and to make the community welcoming to people with disabilities. In regard to carrying out this purpose effectively in a well-governed body, the Executive Committee itself came up as a topic from a few individuals, themselves not executive committee members.

This group consists of the chairman, vice-chairwoman, secretary, and parliamentarian, but these roles seem unimportant and fluid. From the meetings I attended, the only role of any of these positions was the chairman (vice-chairwoman in his absence), who read the agenda and approved motions. Several members believed that certain duties fell upon a particular officer, such as the secretary taking the minutes or the chairperson writing the agenda. However, upon examination of these roles, it seems that all of the officer duties are carried out by the city liaison, who is not even an actual member of CODI. This individual is the one who takes the minutes, who types the agenda before meetings, and maintains parliamentary procedure at meetings. One would think that these duties should fall on the secretary, chairperson, and parliamentarian, respectively. In order for any city body to function effectively, its members must fully participate and labor above and

beyond a simple consultative role. Its members must put forth effort in addition to only attending meetings and offering comments.

Should the executive committee be the example of attendance and participation? Out of the executive committee members, in the three meetings I attended, only one individual out of the executive committee was present and on-time consistently at all three meetings. The first principle of changing government agencies and organizations that Lauer (1991) mentions is that, "Changes are more effective when members participate in the organization at a high rate" (as cited in Curry, Jiobu, & Schwirian, 2008, p. 499). So from a sociological standpoint, the answer is an affirmative yes for CODI member participation in relationship to the body's overall efficacy.

The last stream of thought from the interviews was responses to the question, "Should CODI have some sort of authority or power? Is it satisfactory to be a purely 'advisory' council?" Many thought that actual power and the authority to effect change would be desirable, with the first step being to have some sort of budget allotment to "do stuff" with, as one respondent reiterated. Others believed that to wield influence was far superior to political power. All admitted that to give CODI statutory authority would change how the body is structured, such as making it an elected or a mayorally-appointed body. Currently, council members are nominated and elected by existing members, then confirmed by the mayor. If this change in structure were to come to fruition, some believed that CODI's purpose would have the potential for corruption if the individuals had to campaign for their seat or "know the mayor." Difficult as it may be to politically empower this group of individuals, many agreed that individuals would be much more invested in the purpose and goals of CODI if this presence of political power were to come through.

## Conclusion: Social Movements and Change

“I believe CODI is on the cusp of change toward more power in Knoxville,” said one respondent. How to effect this change? Respondents seemed to gravitate toward one of two schools of thought regarding change: bureaucracy or social movements; most consider themselves in between. Can one be an effective advocate for change and belong to both schools? Rev. Dr. Martin Luther King, Jr., after all, was in both. At times he met with the presidents, while other times he marched in the streets and protested for change. Surely there is not just an “either/or” solution, but rather a “both/and” solution. Frustration with the inability to do more was a common sentiment among respondents, regardless of where they stood on modality for change and regardless of their lack of consistent participation. We found that people use their own power to negotiate ongoing change over time, wherever they may fit in.

CODI exists between the bureaucrats and revolutionaries. It is a case study of a larger problem in social change—that of organizations trying to find a niche in between these two modes of change while differing in opinion about which mode of change is best. There is action (radical) vs. structure (bureaucrat), without (people seeking to transform institutions from outside them) vs. within (inside legislative bodies). Motivation for change is another issue altogether. As many sociologists agree, “Many people accept their lot in life because they have been socialized to accept the legitimacy of existing institutions, and they do not question the status quo” (as cited in Curry, Jiobu, & Schwirian, 2008, p. 501).

It is my opinion that Freire’s Pedagogy of the Oppressed (1968) is the best model for changing the lot of people with disabilities in America. He says that action is not only helpful, but absolutely necessary to initiate social change. Educating the opponents of such change in a clear but

firm and purposeful manner remains essential to the goals which CODI and the greater disability movement purportedly have. According to CODI Bylaws, one such goal is “to promote coordination, communication, and cooperation in working toward common goals concerning persons with disabilities” (CODI, 2004, p. 1). As quoted previously, when government bodies create advisory councils on various issues, these councils have the potential to become strangers to the very people for whom they were chosen to advocate and protect; such estrangement must be avoided at all costs. In my opinion if this estrangement is carefully avoided and education is wholeheartedly pursued, social change cannot be far off. The critical illustrations below serve as a means for how Freire’s model could be utilized more fully by CODI.

How would one go about changing CODI itself and should that be the desired goal? Angry protests in the street, consisting of individuals en masse with disabilities, would elicit ridicule, if such an unlikely unity even came to the fore; yet this may be what is necessary. Education in what may be termed “disability literacy” has been somewhat efficacious thus far. To help one understand another’s plight is the basis for truly effective social change. This is notably embodied in the very successful efforts of charismatic leaders such as Martin Luther King, Jr. (civil rights), Mohandas Ghandi (civil rights, Indian independence) and John Paul II (ending communism).

How many of these leaders’ successful efforts have the Council on Disability Issues carried out? While CODI efforts are laudable, there are still some ways that productive criticism might improve their efforts. To offer some critiques from my point of view, the Council has not initiated direct action and is not prepared to suffer any social (or otherwise) consequences, nor has it engaged in demonstrations, strikes, boycotts, or any sort of civil disobedience. They have not taken over any of the government’s functions and, in fact, have no role in governance other

than to give advice. They have not published large-scale propaganda or any sort of a Knoxville Disability Day awareness campaign; however, they have had moderate success with a once-yearly mentoring program where people with disabilities are paired with a disability-friendly employer mentor and do job shadowing. The most activism that they have done recently is to write a white paper to the mayor, which did have some impact in delaying construction of a transit facility that might otherwise have been inaccessible to people with a disability. At most, CODI has been successful in carrying out the first element of conflict resolution. One of nine (11%) is not exactly admirable.

Future research should examine similar bodies in other cities and in other regions of the country. What kind of cities have a Council on Disability issues—small towns, metropolises, cities? How are these councils similar to CODI in their civil authority, influence, and composition? It would be interesting to see what other bodies have done in terms of policy change and influence on real and actual city ordinances, such as going above the minimum ADA threshold for building accessible city structures.

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# Infusing Disability Culture into Multicultural Courses in Counselor Education Programs

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## Research Articles

**Abstract:** The article addresses the absence of discussion of disability culture and related issues in a counselor education training program at the University of Wyoming. It is likely that counselors will work with people who have disabilities because people with disabilities constitute the largest minority group in the United States. To assess the current level of awareness and perceived level of benefit of infusing disability culture into the counseling program, 19 masters' students participated in training on disability culture, and then discussed what they learned in focus groups. The students reported subscribing to several common stereotypes about disability and expressed the belief that learning about this population is an important aspect of a counselor education program.

**Key Words:** counselor, disability culture, cultural competence

### Introduction

Almost 50 million Americans over the age of five have a disability. People with disabilities comprise more than 19% of the entire population, making them the largest minority population in the United States (Waltrop & Stern, 2003). The Council for the Accreditation of Counseling and Related Educational Programs (CACREP, 2001) alludes to the recognition of disability as a multicultural issue that programs should include in their counselor preparation. CACREP lists "mental and physical characteristics" and "unique characteristics of individuals" in the Social and Cultural Diversity section of its standards. According to the American Counseling Association (ACA) Code of Ethics (2005), counselors are expected to have a certain amount of competency in multicultural and di-

versity counseling (E.11.c). Although the ACA Code of Ethics recognizes disability as a culture (E.8), educators sometimes fail to consider disability in the context of discussing multicultural issues.

Some terms related to disability are potentially confusing and often misused. *Impairment* is the actual physical or structural difference that a person with a disability has (Olkin, 1999). An example of impairment is a person having a leg amputated. The term *disability* refers to the consequences or changes, real or perceived by the individual and others, in performance resulting from the impairment (Olkin, 1999; Reeve, 2000). For example, a person who has had her legs amputated would lose functioning of her legs. Some disability scholars would also include the reactions and attitudes of other people to the impairment as a component of disability. In this context, an example would be a person who has an impairment not being hired for a job that he or she is capable of doing—this employment discrimination is part of the disability. The term *handicap* refers to an environmental obstacle or barrier that prevents a person from participating in activities or from going certain places. An example is a theatre with no ramp to the stage, preventing a person who uses a wheelchair from performing on the stage (Olkin 1999).

According to the Olkin (1999), the term *full inclusion* refers to participation by persons with disabilities in all aspects of society (i.e., social, political, economic, educational, entertainment, recreational, and personal) to the extent they want to participate. *Accessibility* refers to both a lack of environmental barriers preventing people from participating in activities and a lack

of attitudinal barriers that prevent acceptance and equality in treatment and opportunity. The *moral model of disability* contends that disability is caused by a sin or moral transgression, whereby the disability is viewed as a punishment. In this model, disability is viewed as a tragedy and as something to be pitied. The *medical model of disability* views a person with a disability as broken and in need of a cure. The person is viewed as having a decreased value because he or she is not seen as a whole person. The term *minority model of disability* refers to a set of beliefs that peoples' attitudes about disability are more problematic for people with disabilities than the actual impairment is. In addition, this model views the disability as natural and not something that needs to be cured or fixed.

As a person who graduated from the University of Wyoming counselor education program, Sheri Rawlings noticed a lack of conversation related to people with disabilities. Instructors discussed issues associated with racial and ethnic minorities, but the issue of disability was rarely mentioned in the classroom. The training Sheri Rawlings completed at the Wyoming Institute for Disabilities (WIND) forms the foundation of her knowledge about people with disabilities:

“WIND provides teaching, research, information services, and technical assistance to both the University and Wyoming at large. Its major functions include preparing university students to help persons with disabilities live and work in more inclusive communities and providing current information about the broad area of disabilities...to Wyoming residents and professionals” (Wyoming Institute for Disabilities, n.d.).

However, there is mention of disability in only one of the counselor education syllabi, indicating that the subject may not be a prominent part of the current curriculum.

Absence of training about disability culture in counseling programs does not appear to be a

problem that is exclusive to this western university. Korinek and Prillaman (1992) conducted a study of counseling programs' preparation of school counselors to work with students with disabilities. Although more than 90% of the 238 respondents reported they believed it was important to offer instruction and training in this area, only about 30% of the respondents thought their programs were prepared to offer adequate training around disability culture. A similar study by McEachern (2003) echoed these results with 35% of the 146 responding schools requiring counseling students to enroll in courses related to working with students with disabilities. Some people assume that counselors and other helping professionals are more likely to have positive attitudes about people with disabilities, but according to Nathanson (1979), this does not appear to be the case. Counselors experience the same negative images and stereotypes about people with disabilities as people in the general public. Although counselors are encouraged to examine their racial and ethnic biases and stereotypes, often the discussion of stereotypes about disability are left unrecognized and unaddressed (Reeve, 2000). Although the Nathanson (1979) study, is over 30 years old, the results of this current study suggest that counselor attitudes have not changed over this period of time.

The purpose of the current research project was to pilot a program for increasing counselor students' awareness about the importance of including disability culture in the current curriculum. Counseling students had the opportunity to discuss their perceptions of the potential benefits of such an addition. The long term goal of this research is to have the topic of disability culture added to the multicultural course at the University of Wyoming, as well as other courses in the program. The purpose of adding disability culture to the curriculum is to increase counselor competence in working with clients with disabilities. This increase is expected to lead to greater client satisfaction and reduction of biases and oppression. According to Beecher, Rabe,

and Wilder (2004), a “lack of disability knowledge and training may increase counselors’ discomfort in interacting with persons who have disabilities” (p. 85). Since people with disabilities make up the largest minority population, it is very likely that counselors will interact, directly and indirectly, with people who have different types of disabilities.

### **Disability as a Culture**

Barnes and Mercer (2001) state that, “Disability culture presumes a sense of common identity and interests that unite [people with disabilities]...” (p. 522). DePoy and Gilson (2004) described culture more specifically as, “A circumscribed group in which members share common experiences, symbols and meanings, tacit rules, language, history, discourse and cultural identity” (p. 81). Disability culture shares many obstacles experienced by other minority cultures. People with disabilities face prejudice, discrimination, and stigma due to their impairments. They may be overlooked for jobs because employers either underestimate what the person is able to accomplish or feel uncomfortable about the disability (Olkin, 1999). Other common characteristics of minority populations include a shortage of public role models with whom to identify, a lack of representation in professional roles, and political under-representation (Olkin, 1999). People with disabilities are also underrepresented in groups used in normalizing assessment instruments, therefore are often subjected to inappropriate use of tests (Olkin, 1999).

Disability, as a cultural minority, differs from ethnic minority populations in some ways too. Disability is a category that a person can enter into and exit. A person can get into a car accident at any time, become paralyzed, and become a person with a disability. A person who has lost the use of an arm may regain use of it through surgery and no longer have a disability. People with disabilities are often subject to separate but equal status, as evidenced by separate

transportation, entrances, and water fountains. A person with a disability is often the only person in an immediate family or neighborhood that has a disability. There is rarely a preexisting sense of *disability pride* in the family. Some people who have disabilities do not self-identify as being disabled (Olkin, 1999). People who are able to carry out all the functions of every day life that permit them to live independently, may not feel that they have a disability.

Some counselors may think it unnecessary to learn about this population because counselors are supposed to have unconditional positive regard for all their clients. Unconditional positive regard is a term that is common to the field of mental health. It refers to the idea that all people have value and should be treated in an accepting and caring manner. This regard is important, but not sufficient, because the counselor needs to make certain behavioral and physical accommodations that they may be unaware of unless taught (Reeve, 2000). A large number of problems that people with disabilities experience are environmental and outside of their control. For example, buildings without elevators or ramps, aisles too narrow for a wheelchair, lack of accessible parking, and signs without Braille. Most counselors focus on facilitating personal change within the client, but if the counselor does not recognize or address the environmental stressors, the client may not feel heard (D’Andrea, Skouge, & Daniels, 2006). Counselors’ lack of knowledge about the needs of this population further alienates and marginalizes people with disabilities.

### **Marginalization of People with Disabilities**

Historically, people with disabilities have been devalued and marginalized. They were locked up in asylums, put on display in “freak shows,” and involuntarily sterilized to prevent reproduction (Fishley, 1992). Today, people with disabilities are frequently misrepresented in the media and are rarely portrayed as everyday human beings (Shapiro, 1994). The media often portray people with disabilities according to

stereotypes --as persons suffering from personal tragedies, as sources of great inspiration, or as mean and embittered recluses who are miserable because of their impairments (Reeve 2000; Shapiro, 1994).

Marginalization continues to occur in multiple ways. For example, stigma surrounds people with disabilities enjoying a sex life and wanting to reproduce (Ward & Pointon, 2004). Eugenics is still being practiced in the United States. Eugenics is a belief that a higher quality of the human species can be created by preventing people with certain characteristics from reproducing ("Eugenics," n.d.). This is evidenced by the common practice of doctors testing for abnormalities in fetuses by way of amniocentesis. If fetal abnormalities are present, doctors sometimes recommend the mother terminate the pregnancy by way of a therapeutic abortion. The term therapeutic abortion refers to an abortion performed to prevent the birth of an infant with a birth defect ("Therapeutic abortion," n.d.).

Leaders of the disability movement want to move away from the mindset of disability as devalued to that of equal value (Olkin, 1999). The disability movement is striving toward full inclusion (Olkin, 1999). People with disabilities want to be able to participate in all aspects of life to the extent the person desires, not limited by environmental and attitudinal barriers. The minority model promotes the mindset that disability is natural and people with disabilities should be seen as people first.

### **It Is More than Just a Name Change**

Person First Language (PFL) puts the person before the disability. The purpose of PFL is to reaffirm that disability is not the most important aspect of a person. Non-PFL is common in most medical settings. It is part of the practice in which professionals refer to clients by their symptoms: the cancer patient, the schizophrenic man, the alcoholic family, the blind client. A study by Arokiasamy, Strohmer, and Guice

(1994) examined how clients with disabilities perceived their counselors' credibility. The counselors used different types of communication styles, varying between ultra-correct (euphemistic terms for disability), correct (PFL), and incorrect (Non-PFL). The researchers concluded that the different types of language use did not significantly impact the clients' perceptions about their counselors' credibility.

Perhaps these results are indicative of the need for deeper changes. Person First Language is more than a language style; it is an attitude and mindset. Changing the terms without changing the attitude does not change the message. A personal experience comes to mind that supports this view. One week after receiving training on disability etiquette and PFL, a counseling student was talking about a sports event she had watched the previous night. Commenting on the way the players performed she stated, "Those guys played like a bunch of special needs kids." She changed the terminology; she did not say "retards," but her attitude about people with disabilities had not changed. She was still demonstrating the attitude that people with disabilities are "less than" people without disabilities. If a counselor is not demonstrating an accepting attitude, using PFL will probably not improve the relationship between the counselor and the client.

### **Stereotypes and Biases about People with Disabilities**

Counselors need to examine their personal biases about people with disabilities in order to competently counsel people in this population. As is the case with other minorities, there are a number of stereotypes and assumptions about people with disabilities. The researchers limit the discussion of these myths to those most prevalent in and relevant to the counseling setting.

### *Disability as a Piece, Not the Whole*

In general, people without disabilities often perceive the disability to be the person's biggest issue. However, people with disabilities often feel that other peoples' attitudes and inaccessible environments are the biggest problem they face (Swain, Griffiths, & Heyman, 2003). While people with disabilities most often view disability as one spoke in the wheel of their lives, people without disabilities perceive the disability as the hub of the wheel (Olkin, 1999). It is important to remember that all people have multiple roles and identities.

More specifically, when a person with a disability comes to counseling, counselors often assume that the disability is the presenting problem (Smart & Smart, 2006). The counselor may assume that the disability is causing the problems that the client has reported (Reeve, 2000). The disability may or may not have anything to do with the counseling issue. If a person with a disability is experiencing symptoms of depression or is feeling angry, counselors may assume this to mean the person has not "come to terms" with his or her disability. Counselors sometimes forget that personality characteristics range as much for people with disabilities as they do for people without (Olkin, 1999).

### *Having a Disability Does Not Imply a Lower Quality of Life*

It is inaccurate to assume that a person with a disability has a lower quality of life than a person without a disability. People frequently make comments that indicate they think this way such as, "I would rather be dead than live like that." Many people with disabilities are not waiting to be cured or fixed. Judy Heumann, a disability rights activist stated, "Disability only becomes a tragedy for me when society fails to provide the things we need to lead our lives – job opportunities or barrier-free buildings, for example. It is not a tragedy to me that I'm living in a wheelchair" (as cited in Shapiro, 1994, p. 20). The tragedy assumption is prevalent

even among counselors, as found by Parkinson (2006), where 75% of the 25 participants, admitted to viewing disability in terms of tragedy or irrevocable loss.

### *One Impairment Does Not Imply Impairments in Other Areas*

Disability as a characteristic has a large "spread." "Spread refers to the power of single characteristics to evoke inferences about a person" (Olkin, 1999, p. 55). For example, a common assumption is that if a person has one disability, it leads to impairments in other parts of that person's life. Some people assume that a person with a visual impairment also has a hearing impairment, as demonstrated when people talk slowly and loudly to a person who has a visual impairment. People with speech impairments are often assumed to have cognitive impairments. Speech impairments can be caused by a variety of disabilities that do not impact cognitive abilities. "Our society automatically underestimates the capabilities of people with disabilities...A disability, of itself, is never as disabling as it first seems" (Shapiro, 1994, p. 18).

Another common misperception is that people with cognitive disabilities are eternal children or childlike. This is apparent when adults with cognitive disabilities are given children's toys and stuffed animals. Sometimes people will even talk to a person with a cognitive impairment in baby talk or talk about that person right in front of them. People with cognitive disabilities are often concerned about the same issues as people without these impairments: intimate relationships, paying bills, and getting along with coworkers. It is important to keep in mind that there are varying degrees of impairment associated with cognitive disabilities, as apparent by the different levels of severity described in the Diagnostic and Statistical Manual of Mental Disorders(DSM-IV-TR) (American Psychiatric Association, 2000).

## The Current Study

In order to increase counselor awareness about disability culture, Sheri Rawlings presented a one-hour training on disability culture to first year masters' counseling students at University of Wyoming. The goal of the training was to have students examine their personal beliefs and biases about people with disabilities. The training included a discussion about common myths held about people with disabilities. The training was firmly grounded in the minority model of disability studies and included the rationale behind why disability qualifies as a culture. The session included a summary of how the disability movement has changed over time.

### Method

Eighteen first-year masters' students and one second-year masters' student in a counselor education program volunteered to participate in this study. Participants were recruited by one of the researchers going to both of the counselor practicum classes and asking for volunteers. The classes were told that the research would include training about disability and would include focus group discussion. Every student from the practicum classes voluntarily participated in the research study. This study did not have a control group. Descriptive data was not collected about the participants for this research study. Participants did not receive monetary compensation for their participation. They were provided a pizza lunch since the research study took place during lunchtime.

### Materials

#### Vignette

Participants received a vignette describing a client coming to counseling. This vignette depicted typically occurring presenting concerns: the client with a diagnosis of Mental Retardation was experiencing job dissatisfaction, relationship problems related to communication problems, and dissatisfaction with her sexual

relationship. The vignette included four discussion questions to gain understanding of the way the participants conceptualized the case, what other information they would like to know about the client, ethnic and cultural concerns related to the client, and possible resources and recommendations that the counselor would explore with the client.

#### Disability Etiquette Handout

Participants received a two-sided, one page handout about disability etiquette. The purpose of this handout was threefold: to eliminate the participants' need to take notes, to increase their participation during the presentation, and to provide them with something to remind them of their learning.

#### Disability Culture Training

Participants learned for an hour about disability culture. This training focused on multiple aspects of disability culture, including disability etiquette, stereotypes, myths, and person first language. The presentation included a definition of disability culture and rationale for why it qualifies as a culture. The presenter also introduced the participants to the three most common models of disability studies: moral, medical and minority. Participants watched video clips from two videos; *Without Pity: a Film about Abilities* (Mierendorf, 1996) and *Murderball* (Mandel & Shapiro, 2005). Both of these movies feature people with disabilities. The researcher also presented counseling concerns of people with disabilities that are similar to the concerns of people without disabilities and those that would differ between the two populations. Examples of differing counseling concerns included stress from prejudice and discrimination about the disability, living with chronic physical pain, end of life issues, and not having relatives or family members with a disability with whom the person can identify.

#### Focus Group Discussion Questions

Each group received the same set of questions to facilitate the focus group discussions.

The participants were asked to reflect on their previous experience with disability, both personally and in the counselor education program. The participants discussed what knowledge they gained from the presentation and they shared how the information they learned would impact their counseling skills. The participants were asked about what past stereotypes and myths they had been exposed to. They also discussed what information they thought was most important to share with other counselors.

### Procedure

After obtaining informed consent, participants were given a vignette describing a client coming in to counseling. The participants were given 15 minutes to answer the questions at the bottom of the vignette. The participants were instructed to use a different color pen to add notes or make changes to the treatment plans for their vignettes as the training progressed. The researcher presented a one-hour training on disability culture. Following the lecture, participants were randomly divided into five groups. Four groups had four participants, and one group had three participants. Each group had a group facilitator who facilitated group discussions of the set of questions. The discussion was limited to 30 minutes. After the participants finished their discussions in their groups, the researchers allowed them to make changes to the treatment plans, based on the knowledge gained from the training.

### Results

Two participants did not return the vignettes at the end of the research study as the researcher only received 17 back from the participants. Nine of the 17 participants (approximately 52%) mentioned disability or Mental Retardation somewhere in the treatment plans for the vignettes. Five of these nine participants were interested in knowing the severity of the Mental Retardation of the client in the vignette. Three of the nine participants wanted information

about how the fiancé views disability. Only two participants recognized disability as a culture in the treatment plans. Only one participant made changes to the vignette after receiving the training, limiting the amount of discussion about this part of the research.

### Discussion

In addition to the 19 research participants, five staff members from the Wyoming Institute for Disabilities (WIND) were present throughout the presentation. These people were also the focus group facilitators. One of the counseling education department professors was also present in the training, but did not participate in the focus group discussions. Having these additional people present during the training may have led some participants to be nervous, and possibly not share as much as they may have otherwise.

The researcher does not know why two participants did not return the vignettes. One of these participants is likely to be one who showed up to the presentation late, and that person may not have had time to complete the treatment plan.

Only one student made changes to the vignette after the training. The researcher allowed the students to make the changes throughout the presentation, but did not set aside a specific time for the participants to make the changes. It is likely that more participants would have made changes to the treatment plans had time been allotted specifically to that. The lack of changes on the vignettes made it difficult for the researcher to track any mindset changes the participants may have had during the training.

### Participants' Experience with Disability

The first question asked participants to discuss their experiences with disability, both personally and in the counselor education program. All but one of the 19 participants stated they had personal experience with people with dis-

abilities. Many of these experiences included occupations that led to interactions with people with disabilities. The participants discussed working with youth with hearing impairments, directing recreational activities for people with various types of disability, and working with children in special education classroom settings. Some participants discussed more personal interactions with family members, friends and classmates with disabilities, and one participant mentioned that he had a disability.

Only four of the 19 participants stated that they had experiences with disability in their counselor education program. One student reported having a classmate with a disability, who shared information about her disability in a class. One student reported having a client with a disability in her pre-practicum class. Two students reported learning a small amount about disability in the diagnosis and psychopathology course in the program. One student stated, "This is the first that I have encountered, except for maybe in diagnosis we talked about some of the disabilities people might experience because of a diagnosis" (personal communication, November 7, 2006).

### **What Participants Learned About Disability from the Training**

The second question asked participants what they learned about disability from the training. Eight participants expressed that they were surprised that not all people with disabilities want a cure for their impairment. One responded stated, "That is something I wasn't at all aware of ... their not wanting to change their disability." Four participants stated the training was their first exposure to person first language and four participants reported they had never heard about the models of disability studies before. Three participants stated that they would have assumed that a person with a disability coming to counseling would be coming to counseling to discuss problems related to the disability. Other statements participants made included the different myths and stereotypes about disability,

the importance of education about disability and disability etiquette, how attitudes about disability impact the way people with disabilities are treated, and learning the importance of asking the person before helping. A participant said, "I would usually just do it for them instead of asking them if they want help. It really made me aware that I assume a lot about their abilities"

### **Participants' Prior Attitudes and Stereotypes about People with Disabilities**

The third question asked participants about attitudes and stereotypes they had about people with disabilities prior to the training. Seven participants stated that they had previously assumed that a person with a disability would want to be cured if the opportunity were available. One person stated, "I had never thought that someone would not want a cure...I will be thinking about that for awhile." Another person similarly stated, "I always assumed that of course they would want to be back to normal or whatever. I think that was my own assumption that needed to be challenged."

Five participants stated that they had previously used inappropriate language to refer to people with disabilities, or would use words that refer to types of disability as put-downs for people (i.e., not using person first language, calling a person a "retard," or telling a person their idea is "retarded"). Three participants said they had assumed that people with disabilities were unhappy and had a lower quality of life than people without disabilities. One person stated, "I made the assumption they are probably not happy and they would want to be different." Two participants stated they assumed that a person's disability would be the reason why that person would come to counseling.

Other statements the participants made included previously treating adults with disabilities as children, seeing the person as a disability and not as a person, speaking to an interpreter instead of the person with a hearing impair-

ment, and feeling sorry for a person because they have a disability. A participant mentioned that he had an “instantaneous reaction to treat someone childlike or talk to them in a different way than I would someone else. “I have to stop and tell myself to talk to this person just like they are, as an individual.” Another participant mentioned having a brother that had multiple disabilities that are not visibly apparent. He said, “I noticed when I tell people before they meet my brother they are going to treat him different than if I just let them figure it out.”

Two participants stated that they had previous stereotypes and had made assumptions about people with disabilities prior to the training, but they did not specify what those were. Six people in several different discussion groups brought up an interesting topic that was not addressed in the presentation. When participants were talking about people with physical disabilities, they would say they had “never thought of the person as being disabled.” That viewpoint was typically presented when the participant was commenting that the person with the disability was intelligent and “perfectly functioning.” The researcher has recognized a need to further educate the counseling students about people with cognitive impairments. It seems once the participants became more comfortable with physical disabilities, they viewed that type of impairment as more acceptable. It is possible that the training did not spend enough time going over cognitive impairment for the participants to become more comfortable with people from that population.

### **How Participants Intend to Use the Information Learned in the Training**

The fourth question asked participants to comment on how they intended to use the information they learned in their counseling practices. Each participant was able to identify a way in which they could apply the knowledge gained from the presentation. These applications seemed appropriate for the field and fairly easy to implement.

Eight participants stated that they would not assume that a person’s disability is the reason the person is coming to counseling. A participant mentioned the importance of “considering the fact that the disability is not the reason they are there. There are other things, regular life things that come into play.” Another person stated, “It’s not the very first thing you need to ask about. Assess what they are there for and if they bring it up, fine. But don’t make it an issue if they don’t feel it is one.” Two participants stated they would use the etiquette tips and person first language with clients. Two participants said they will treat people with disabilities like “normal” people. Other things participants said they would do is learn more about people with disabilities, not treat adults with disabilities like children, not make assumptions about the person, and not assume the person wants a cure for their impairment. A participant stated, “It has challenged some of my assumptions. Most of the time I like to think of myself as colorblind, and that I treat everyone the same. I’m wondering as a new counselor if someone came to me who has a disability, what would be my first human reaction or assumption.”

One participant who has a client with a disability plans to change the questions she was going to ask her client in their next therapy session. She said, “I’m already thinking about how much I am going to change things with the client I am working with now. The questions that I was planning on asking in the next session, I am not going to ask those.” The researcher felt it was significant that this one participant was planning to change the focus of the therapy session after receiving the training. This may indicate the training impacted her view of disability to a strong degree.

### **What Participants Think is Most Important for Counselors to Know about Disability**

The last question asked participants to discuss, in one minute, what they would tell incoming counseling students about disability. Several new topics came up in the discussion

about this question. Participants focused on how important it is for counselors to learn about people with disabilities. One participant stated, "I would say that it is a critical piece of the content of the program and they should also seek additional opportunities to learn more information." Each participant was able to identify at least one area that they felt was critical to a counseling program. The responses to this question indicated the participants truly believed it would be beneficial. Five participants stated they would encourage new students to learn about disability. One person said, "We have to learn about it because we are going to have clients who are going to be looking to us, so they don't have to be continually educating us, so we can get to the work of counseling." The following three recommendations were each brought up by four participants: (1) exploring their personal attitudes and stereotypes about disability, (2) viewing the clients' disability as a piece of the person, not the entire person, and (3) not assuming the disability is the presenting problem. The following three recommendations were each brought up by two participants: (1) acquiring knowledge about disability is a critical piece of counselor education training, (2) using person first language, and (3) not assuming a person wants a cure for a disability.

## Conclusion

The research showed that the counseling students at the University of Wyoming knew little about disability culture. The participants indicated that they valued the material they learned by the comments made in the focus group discussions. This would indicate that incorporating disability content into counselor education programs would be well received by most students. The students were able to identify ways in which they could benefit from learning about this population. There are topics of disability that need further attention, especially information about cognitive impairments. Several professors in the counseling department have since mentioned that the students still bring up top-

ics addressed in the training during their classes. This indicates to the researcher that the participants find the material applicable to their profession.

A one-hour training is not sufficient to teach counseling students all they need to know to adequately prepare for working with people with disabilities. It is important that these topics continue to be addressed in multiple courses and contexts within the program. Overall, the project seems to have made a positive contribution to the counseling students and the researchers hope this will continue in the program for years to come.

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At the time of the study, **Terri Longhurst** worked at the University Of Wyoming, Wyoming Institute for Disabilities as the Associate Director of Disability Studies and the Coordinator of Interdisciplinary Training. She is now the Executive Director of the Hospice of Laramie. She has a MS degree in Child Family and Consumer Sciences with an emphasis in Family Policy from the University of Wyoming and is currently completing her PhD in Educational Leadership, Renewal and Change at Colorado State University.

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# Ethnographing the Garden

Rama Cousik

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As I serendipitously encountered unique contexts during my dissertation research, I began to gain a deeper understanding of the families of children with disabilities who are participating. One day, I extended my work to a participant's garden and continued my quest. We happily dug, tilled, weeded and planted together as we talked. The process of working with the earth put us both in a relaxed and comfortable mood. I began the interview in a natural, conversational tone. Appearing to feel completely at ease, the mother began to share some of her thoughts about her child, his school and the problems with the system.

Digging the earth

Seeking to know her well

Tilling the land

Mulling over our conversation

Weeding the earth

Airing her misgivings

Planting peppers

Sowing seeds of trust

Binding the earth

Bonding with the family

Hoping for a good harvest

Hoping to enjoy the fruits of our labor

**Rama Cousik** is an Assistant Professor in Special Education. She received her Ph.D. from Indiana University Bloomington in 2011. She teaches an undergraduate course on teaching methods for students with special needs and an undergraduate/graduate course on transition. Her research interests include the impact of culture on the education of children with disabilities.

## Book Review

**Title:** *Moon on the Meadow: Collected Poems*

**Author:** Pia Taavila

**Publisher:** Gallaudet University Press, 2008

**ISBN:** 978-1-56368-364-0, Paper, 140 pages

**Paper:** \$24.95

**Reviewer:** Aimée Gramblin

When I was an elementary-aged child, my Dad and I took an American Sign Language class. Learning the alphabet was all it took for me to become captivated and mesmerized by the language. When *Moon on the Meadow: Collected Poems* came to my attention and I saw the author, Pia Taavila, was an English professor at Gallaudet University, I was immediately interested. My curiosity was satisfied by a collection that offers a window into disability culture as perceived by a hearing Child of Deaf Adults (CODA). *Moon on the Meadow* winds around many universal themes, including childhood, having children, familial roots, romantic involvements and dissipations, experiences of learning and teaching, and communion with nature. We are given glimpses into the deaf community on a personal and general level. Although these poems do not dominate the collection, Taavila's highly imagistic poetry is informed by her experience as a CODA.

In her astute and beautifully written introduction, Taavila cites Ezra Pound as one imagist poet from whom she draws inspiration. Amy Lowell is another imagist poet who comes to mind when reading Taavila's poems. On the predominance of images in her poetry, Taavila states:

“It is a seeing and seeing again, that shapes my work. It is the direct result of being raised by deaf parents, whose entire method of communicating with me was primarily through our hands and eyes, through a touch on the shoulder. Concrete. Tactile. Animated. Expressive” (p. xxv).

Earlier in the introduction, we are provided with helpful insights into Taavila's dance between

the hearing and deaf community: “my overall feeling is one of gratitude for and celebration of being a quasi-member of two cultures, even as that identity was often one of confusing and overlapping allegiances” (p. xxii). This sentiment resonates in Taavila's poem “The Deaf Club Sails to Bob-Lo Island”:

“When Daddy spun and dipped her low,  
she came up laughing.  
How did they know  
to move their feet, which steps to take?  
How did they feel the drum line's beat? I  
saw them dance to private music” (p. 19).

The poet's reverence for her parents' private language is obvious here; we feel a longing from Taavila to be an exclusive part of her parents' deaf culture, while she is instead faced with the ongoing struggle of being “other” in both the hearing and deaf communities, thus providing an important poetic tension which holds together the entire collection.

The writing in *Moon on the Meadow* is self-assured and varied, serious and playful. As Taavila works within traditional poetic forms, such as Haiku, she also stretches their limits. *Moon on the Meadow* consists of many previously published poems and lends itself to being read in snippets as each piece stands on its own. All the poems are presented in a continuous stream, which feels a bit overwhelming at times. For such a dense collection, guideposts such as section divisions would have proven useful. But this is only a minor annoyance. Taavila's collection, observant and vivid, promises to have a far reach into several audiences, including those interested in disability culture, poets and poetry enthusiasts.

**Aimée Gramblin**, English M.A., University of Central Oklahoma, has had Arts columns appear in *Urban Tulsa Weekly* and poems published in journals including *The Mid-America Poetry Review* and *The Rectangle*. She was the 2006 University of Central Oklahoma Creative Studies Program Geoffrey Bocca Scholar. She may be contacted at dna\_gramblin@yahoo.com

## Book Review

**Book Title:** *Representing Disability in an Ableist World: Essay on Mass Media*

**Author:** Beth A. Haller

**Publisher:** Louisville, KY, Advocado Press, PO Box 406781, www.advocadopress.org, 2010

**Paper:** ISBN: 978-0-9721189-3-4

**Cost:** \$24.95; 208 pages

**Reviewer:** Steven E. Brown

*Representing Disability in an Ableist World* consists of 10 essays, most previously published elsewhere, but all updated for this excellent 2010 book. Haller, a newspaper journalist, who has become a professor of media, and a proficient blogger of media issues related to disability, approaches her subjects from a disability rights and disability studies viewpoint. While Haller clearly empathizes with the disability rights movement and is clear in her writing about her position, she is also able to provide a well-nuanced, balanced approach to each of these issues/essays.

Many chapters are based on qualitative or quantitative content analysis as well as the author's interpretation of subjects ranging from assisted suicide to movies (or more specifically movie: "Million-Dollar Baby") to telethons, humor and more. Several essays focus on disability in news media, including case study of autism and inclusive education.

In the chapter titled, "Changing disability terminology in the news," Haller explains why language is so important to disability rights activists:

"Language has always had the power to define cultural groups. The words used to refer to a group of people are important: they have ramifications for self-perception, but they also play a large role in shaping what the general public believes about the group....The language in sto-

ries about disability, they say, helps shape what the public understands about the disability condition" (p. 49).

In our media-based, social-networked society, understanding how disability is represented in the media is of great import and Haller's book would be useful in courses ranging from disability studies to journalism to history to economics (the chapter on advertising) and many more.

**Steven E. Brown, Ph.D.** is an Associate Professor of Disability Studies at the University of Hawai'i Center on Disability Studies, an Editor of RDS, and co-founder of the Institute on Disability Culture. He may be contacted at [sebrown@hawaii.edu](mailto:sebrown@hawaii.edu)

## Book Review

**Title:** *The Power to Spring Up: Postsecondary Education Opportunities for Students with Significant Disabilities*

**Author:** *Diana M. Katovitch*

**Publication Data:** Bethesda, MD: Woodbine House 2009

**Softcover:** ISBN: 978-1-890627-95-9

**Cost:** \$24.95, 265 pages,

**Reviewer:** Frank R. Rusch

Postsecondary education and employment are typical outcomes of high school students without disabilities and these two outcomes are increasingly important to students with diverse disabilities. Postsecondary education, in particular, has clearly been one of the bright spots in relation to outcomes associated with youth with disabilities transitioning from high school to young adulthood. Newman et al. (2010) reported that 46 percent of youth with disabilities in their 2005 cohort entered a postsecondary institution within four years of "leaving" high school in comparison to 26 percent of their cohort under study in 1990. There should be little doubt that new and higher expectations face our

youth with disabilities, and new resources that will help and guide these expectations will follow. Katovitch's *The Power to Spring Up* is an excellent example of these expected resources.

*The Power to Spring Up* is presented in three parts: Part One contains three chapters that introduce the reasons for attaining a higher education, the laws that support this quest, and practical considerations related to attending an institution of higher education; Part Two contains 11 chapters that profile programs across the country to illustrate diverse options available; and Part Three provides important detail related to the roles that must be assumed by students, their parents, and teachers. One of the six chapters found in this third section provides detail related to financing (chapter 18) and one of the most interesting chapters in this section provides important advice to parents who are unsure how to support their children and even how to "let go." Katovitch provides a long list of references for parents throughout the text, including *Letting go: A parent's guide to understanding the college years* by Karen Levin Coburn (2009).

*The Power to Spring Up* is appropriate for parents and any educator counseling youth to attend postsecondary education. Chapters include specific examples of how youth with "significant disabilities," Autism Spectrum Disorders, Asperger's Syndrome, Down syndrome, and Cerebral Palsy manage their enrollment in a number of diverse postsecondary settings. This text is a valuable resource for anyone interested in the nuts and bolts of planning, financing, and generally supporting youth in transition. Parents will be inspired to consider new and rewarding options for their children as these youth grow and find their place in the community. Katovitch deserves a standing ovation.

**Frank Rusch** is Professor of Special Education at Penn State University. His research is focused on comparing and contrasting the outcomes experienced by youth with diverse dis-

abilities transitioning from high school-related programs over the past 30 years, including post-secondary enrollment, employment, dropping out, poverty, and arrest rates.

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## Disability Studies Dissertation Abstracts

Editor's Note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at: <http://www.hsls.pitt.edu/guides/histmed/dissertations/>

*Of deaf lives: Convert culture and the dialogic of ASL storytelling*

Bechter, Frank Daniel. Proquest Dissertations And Theses 2009. Section 0330, Part 0326 578 pages; [Ph.D. dissertation]. United States -- Illinois: The University of Chicago; 2009. Publication Number: AAT 3362460.

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*A study of the achievement of students with disabilities within inclusion classrooms in Alabama public high schools*

Cain, Patrick M., Sr.. Proquest Dissertations And Theses 2009. Section 0302, Part 0514 151 pages; [Ed.D. dissertation]. United States -- Alabama: Alabama State University; 2009. Publication Number: AAT 3362649.

*Attitudes and perspectives of urban special education teachers working with students with Emotional and Behavioral Disorders in an inclusive setting*

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*Teachers' attitudes towards inclusion of special education students and their instructional adaptability to students with disabilities*

Witherspoon, Cheryl Kenely. Proquest Dissertations And Theses 2005. Section 1045, Part 0514 94 pages; [Ed.D. dissertation]. United States -- South Carolina: South Carolina State University; 2005. Publication Number: AAT 3361422.

*Self-advocacy experiences of college students with Learning Disabilities and/or Attention-Deficit Hyperactivity Disorder*

Cano-Smith, Jennifer. Proquest Dissertations And Theses 2009. Section 0061, Part 0745 199 pages; [Ph.D. dissertation]. United States -- Colorado: University of Denver; 2009. Publication Number: AAT 3359920.

*Developing a fascination for literacy: An examination of the literacy learning of an included student with autism*

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*Teaching parents of children with autism to evaluate interventions*

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*The perception of friendships for children with Asperger's Disorder and its relationship with loneliness and depression*

Yeung, Angela W.. Proquest Dissertations And Theses 2009. Section 0474, Part 0622 118 pages; [Psy.D. dissertation].United States - - Connecticut: University of Hartford; 2009. Publication Number: AAT 3363838.

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*Examination of case law (2007--2008) regarding Autism Spectrum Disorder and violations of the Individuals with Disabilities Education Act*  
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*The needs of Korean-American and Korean families of children with disabilities*  
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*Perception of early intervention family outcome: Inside Chinese-American families having children with disabilities*  
Wu, Pei-Fang Rachel. Proquest Dissertations And Theses 2009. Section 0169, Part 0529 193 pages; [Ph.D. dissertation]. United States -- Oklahoma: The University of Oklahoma; 2009. Publication Number: AAT 3365921.

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Presley, Louise Ribeiro. Proquest Dissertations And Theses 2009. Section 0112, Part 0452 274 pages; [Ph.D. dissertation]. United States -- Illinois: Loyola University Chicago; 2009. Publication Number: AAT 3366142.

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*The use of dogs to impact joint attention in children with autism spectrum disorders*  
Welsh, Kenneth Charles. Proquest  
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United States -- Minnesota: Walden University;  
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