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## RDS EDITORIAL

My Pet (Trained)  
Megan A. Conway, Ph.D.  
RDS Managing Editor

A recent article in the Santa Rosa Press Democrat was titled “Fake Service Dogs Anger Owners of Trained Pets”.

(<http://www.pressdemocrat.com/article/20130807/articles/130809625>)

As the proud partner of a “Trained Pet” named Presto, please ignore the head banging. How many times have I snarled, “He is *not* a PET,” to an airline reservationist? I was dismayed by this news. That is to say, I was dismayed that the issue *made* the news. I was not looking forward to another day of explaining myself as I went about my daily activities with my Pet (Trained) by my side.

Most of us who use Guide Dogs or Service Dogs have experienced access challenges of one sort or another. I have had cab drivers holler, “No mutts lady!” as they screech away from the curb when I attempt to hop in. I have had bus drivers refuse to move their buses and customer service people refuse to serve me. Mothers drag their small children towards Presto on a regular basis, cooing, “Looooook, doggie, “ and offering little hands as a succulent treat that fortunately Presto ignores (unless they’ve been eating bacon).

Usually (with the possible exception of cab drivers), an explanation that my dog is a “Service Dog” will get the bus moving. But recently, publicity about “fake service dogs” have brought out the worst in people. For example, a couple of weeks ago I boarded the campus shuttle with Presto only to be stopped at the door by the driver. “You got papers for that dog?” she growled. I pointed to his vest and gave my Service Dog speel. “I need papers,” said the driver again. I explained about my disability. I told the driver about the work Presto does for me. I explained about the ADA (I was on a roll) but the driver would not give up. She did finally move the bus, but she publically humiliated me during the entire ride by continuing to assert my illegitimacy in a loud voice and arranging over the radio for security to meet me upon my disembarkment. I am sure I was the most exciting thing that had happened to her all month. There had recently been a news story about “fake service dogs” in our local paper. And I paid for it dearly.

After I spotted the “Trained Pets” story I became curious. Just how many people out there are actually trying to scam us into believing their mutts are the genuine article? A search for “fake service dogs” led to little data but some interesting commentary.

According to a blog called “Life with Dogs”:

“The New York Post reported that many New Yorkers have been using fake ‘service dog’ tags on their pets so they can take them wherever they want. Dog owners in New York have been purchasing fake tags, vests, patches and certificates on the internet. These New Yorkers put these tags on their dogs so they can take them into restaurants, grocery stores, coffee shops, clubs and other business.”

(<http://www.lifewithdogs.tv/2013/08/people-using-fake-service-dog-tags/>)

What is the matter with these people? Why on earth would anyone want to take their dog to the grocery store? It's like taking a child to the grocery store, distractions around every corner. And a club?? What dog would not go absolutely insane inside a club with blaring music and stupid dancing drunk people? Cafe's, coffee shops and restaurants, I guess if you're a Francophile. But honestly, if Presto did not perform a functional service for me, I would leave him at home asleep on my couch, chewing on one of my daughter's Barbie shoes, where he belongs.

Apparently, some people are so into their dogs that they will break the law to go everywhere with them. Service Dogs Central has an article on "Spotting Fake Certification" with a long list of online sites where you can purchase phony Service Dog certification and equipment. They also feature "scary" verbiage from these sites including (very scary) tidbits such as:

"If your dog exhibits occasional nipping, Service Dog Certification of America recommends muzzling." (<http://servicedogcentral.org/content/node/509>)

Today a CBS news story about fake service dogs made the national news:

"It's an easy law to break, and dog cheats do. By strapping a vest or backpack that says 'service animal' to their pet, anyone can go in stores and restaurants where other dogs are banned, creating growing problems for the disabled community and business owners and leading to calls for better identifying the real deal."([http://www.cbsnews.com/8301-204\\_162-57607109/illegal-fake-service-dogs-pose-dangers-to-many/](http://www.cbsnews.com/8301-204_162-57607109/illegal-fake-service-dogs-pose-dangers-to-many/))

As I stood in line at Starbucks with Presto, waiting to order my afternoon-slump latte, not one but *two* little old ladies gave me the stink eye. "Cheater," their looks said. I gave them the stink eye right back, but it did bother me. I have the vest, the leash, the ID tag and the ID card, all proclaiming that Presto is a genuine Service Dog. He even *looks* like a service dog (Golden Retriever with impeccable manners). What do I need to do to "prove it" to these people? Just because Lazy Larry doesn't want to leave his dog at home so he doesn't have to worry about his carpet shouldn't mean that someone with a disability has to submit a blood test to use public transportation with their Service Dog. How about prosecuting people who sell fake ID cards? How about "Three Piddles and You're Out"?

## RESEARCH ARTICLES

Disability Around the World: Study Abroad in Diverse Cultural Contexts  
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**Abstract:** During a short-term study abroad program undergraduates and instructors from the U.S. explored disability issues in diverse cultural contexts: Ghana, UAE, Nepal, and Thailand. Through qualitative analyses of personal narratives, student interviews, journals, and other products, student- and faculty-researchers learned that participating students developed more critical perspectives on the importance of culture in shaping disability experiences in the U.S. and abroad.

**Key Words:** diversity, international travel, disability studies

Although short-term study abroad programs cannot offer the in-depth or immersive experiences of semester-long or academic year programs, they can have important influences on students' personal and academic perspectives as compared to campus-based experiences. For example, studies have identified positive effects on students' perceptions of their personal development, functional knowledge of different cultures, greater intercultural awareness, increased confidence, and acknowledgment of the importance of reflection for personal and professional growth (Akanke & Slawson, 2000; Chieffo & Griffiths, 2004; Pence & Macgillivray, 2008; Shames & Alden, 2005; Sutton & Rubin, 2004). Thus, Sachau, Brasher, and Fee (2010) suggested three overarching educational goals for student growth through short-term study abroad programs: increasing knowledge, shaping attitudes, and building confidence. Regardless of the length or locale, programs with the greatest impact engage students personally in frequent, structured interactions with local cultures and opportunities to reflect on the meaning of what they are learning (Chieffo & Griffiths, 2009; Jones & Caruana, 2010).

### Program and Disability Studies Context

These goals and approaches were integral to an "around the world" short-term study abroad program that offered undergraduates a comparative exploration of disability. During a five-week winter session, 21 undergraduate students and three faculty instructors from the U.S. visited Ghana, United Arab Emirates, Nepal, and Thailand. Within the broader goals of the program, the instructors had a specific interest in developing students' understanding of disability as a cultural phenomenon. Therefore, activities and academic assignments were framed by two overarching questions intended to challenge students to consider culture as a lived, negotiated, and dynamic process of making meaning: How is the experience of disability influenced by the culture in which one lives? What factors influence the services and supports available to people with disabilities? Because of the short amount of time in each country, which had the potential for creating a superficial tour with limited impact, attention was given to selecting diverse countries and embedding frequent opportunities for engaging with local

individuals and organizations who could provide insider perspectives on disability experiences. Selecting countries where students could engage with cultural features that might be novel to them while part of a supportive program context also created the potential for increasing students' awareness and knowledge of cultural differences and commonalities (Che, Spearman, & Manizade, 2009).

Although the students were not asked to directly engage critical theory approaches to disability studies, the program structure and assignments were intended to support students in consideration of disability experiences as socially constructed, multi-faceted, and consequential at social and personal levels (Hulgin, O'Connor, Fitch, & Gutsell, 2011; Paterson, Hogan, & Willis, 2008). Consistent with Cypher and Martin's (2008) notion of a disability studies pedagogy that promotes students' "critical progress," the program was designed to challenge students to think critically by developing content knowledge about disability while also engaging them in guided questioning about their observations of external situations and their personal assumptions. Gaining and processing content knowledge (e.g., learning about alternative perspectives and experiences of social inequality) can serve as a foundation for critical inquiry in situations where students may be unfamiliar with, resistant to, or have limited opportunity to reflect on cultural meanings of disability (Hulgin, et al., 2011).

This trip was developed by Laura Eisenman, Ph.D. and Michael Gamel-McCormick, Ph.D. as a new offering for students with an interest in disability; no prior study abroad programs at the sponsoring university had a disability focus. The impetus for the new program was the dramatic growth of the university's interdisciplinary, undergraduate Disabilities Studies Minor; in the previous five years enrollments grew from approximately 50 to more than 200. However, the trip was opened to all students, regardless of whether they had declared the Minor. Through a combination of established international connections, acquaintances abroad and domestically, and consideration of air travel routing efficiencies, the faculty selected countries that would maximize comparisons across observable features of cultural processes such as economic resources, social customs, governance structures, religious practices, and disability policies.

The selected countries and primary locations within each included Ghana (Accra), the United Arab Emirates (Dubai), Nepal (Kathmandu), and Thailand (Bangkok). The students and faculty stayed in each country for approximately one week; meeting with individuals with disabilities and their family members, advocacy groups, service providers, government, and non-government organizations. Planned cultural excursions were incorporated into the weekly schedule, and students undertook additional activities on their own. Also, students read assigned academic articles or chapters related to each country including the U.S., completed individual and small group written assignments, and met at least twice each week as a whole class to discuss what they were learning. The fifth week, students and faculty stayed at the University of Hawaii, Manoa, to prepare their final projects and meet with faculty, staff and students of that university's Center On Disability Studies.

### Research Context and Design

Based on many students' final comments about the impact of the program on their personal and future professional lives, the faculty leaders discussed the possibility of engaging students in

a systematic examination of the experience for the purpose of sharing information about the program more widely. A search for research literature on undergraduate study abroad programs that focused on disability issues revealed a small number of studies about students who identified as disabled (Shames & Alden, 2005; Scheib, 2006) and guides on how to include people with disabilities in international exchange and study abroad programs (Mobility International, n.d.). Similarly, a search of the small, but growing literature on disability studies pedagogy identified suggestions for heightening sensitivity to cultural contexts (Hulgin et al., 2011; Paterson et al., 2008), but did not uncover any studies dealing with international study as a means of doing so. Therefore, this case study fills a gap at the intersection of the two literatures by focusing on how a comparative study abroad influenced undergraduate students' understanding of disability.

We positioned our qualitative inquiry as participatory and interpretive (Lincoln, Lynham, & Guba, 2011); acknowledging and capitalizing on the fact that students brought different backgrounds to bear on making meaning of the unfamiliar cultural experiences they encountered on the trip. As interpreters of their own experiences, what would they count as learning? In what ways did they make critical progress in understanding disability experiences? As faculty and student-researchers working together, we elected to foreground multiple student voices through the use of autoethnographic methods that would connect the personal and the cultural (Ellis & Bochner, 2000) and further incorporate other interpretations as identified through grounded theory methods.

## Method

### Participants

Following receipt of institutional review board approval for research involving human subjects, all 21 students who participated in the study abroad received an invitation from the faculty to become student-researchers on the project. The three students who accepted were females in their junior year during the trip. They completed the research as seniors. All three had a Disabilities Studies minor; two majored in human services and one majored in health sciences. None had studied abroad before. All three had relatives with disabilities.

Another eight students agreed to participate in the study through follow-up interviews and permitting their completed coursework, such as journals, to be used as data sources. The other eight participants included one male who was a senior during the trip and seven females, including two seniors, four juniors, and one sophomore. Half had a Disabilities Studies minor. Six majored in nursing or health sciences and two majored in education. Three had prior study abroad experiences. None of the students self-identified as a person with a disability. However, two indicated that they had a sibling, parent or close relative with a disability.

The demographics of the 11 participants were similar to those of the 10 students who completed the study abroad trip, but did not participate in the research activities. Those 10 included eight females and two males; four seniors, five juniors, and one sophomore. Their majors included: education and human services (4), nursing and health sciences (3), and other social sciences (3). Five had prior study abroad experiences. One self-identified as having a learning disability, but did not officially request accommodation. Two indicated they had a

sibling, parent or close relative with a disability.

## Data Sources

During the process of seeking informed consent, potential participants were asked if they would be willing to complete interviews, join a focus group, and share their course-related assignments or other artifacts of the trip such as blogs and photographs. In some cases, participants agreed to share their course assignments, but could not locate some items. In other instances, participants were willing to be interviewed but preferred not to have their journals used for the study. Although all participants agreed to join a focus group, scheduling proved difficult and no focus groups were held.

## Personal Essays and Interviews

Interview questions were developed by the authors in consultation with colleagues who had recently completed a study of undergraduates in a short-term study abroad program. The interview questions covered participants' views about disability before and after the trip, experiences during the trip that influenced how they thought about disability, and their reflections on how those experiences may have influenced other areas of their life (e.g., career interests, personal goals, cultural awareness). Six participants completed interviews in person with the student-researchers or responded to the interview questions in writing.

Prior to interviewing other students, the three student-researchers individually constructed personal reflective essays about how the study abroad affected them. In their essays, the student-researchers identified a key encounter from the trip that they believed to be most personally influential. They reflected upon why the encounter was important to them, how the encounter impacted their professional goals and personal views, and how other aspects of the trip also contributed to their changing perspectives.

## Journals

Nine students shared journals, which had two major components: (1) reflections on their "position" regarding disability and (2) reflections on key messages adapted from materials on the World Health Organization (n.d.) disability and rehabilitation websites. Before arriving in Ghana, students wrote a brief essay to establish their positions (component 1) as an observer of disability experience. Guiding questions for the essay (adapted from Race, 2007) included: (a) What personal experiences and characteristics inform your understanding of disability? (b) What social values, norms or conventions influence your experiences with disability in everyday life? (c) How does your customary physical environment shape your experiences with disability? (d) What are your expectations regarding the lives of people with disabilities in each of the countries we will visit? Initially, for the key messages component, each student selected and commented on three of 11 possible prompts that she or he thought was most pertinent to the lives of people with disabilities in the United States (e.g., *Disability is a human rights issue; Poverty is a cause and effect of disability; Disability affects entire families; Disability is a continuum of experience which varies across the life span*).

Weekly, after visiting each country, students continued to write in their journals about both components. They wrote two to three paragraphs in which they reflected and elaborated on an idea from their original position essays given their experiences in the country just visited and another two to three paragraphs in which they identified and discussed three key messages they thought were most relevant to the lives of people with disabilities in that country.

Each week during the trip, students collaborated in small groups to write summary notes about field visits and activities in each country and to write a brief story about an encounter that had a strong impact on one or more members of the group. In those cases where students participating in the research project included these items in their own journals, these materials served as supplemental journal data. One of the student researchers also shared her blog of the trip.

### Other Course Materials

Prior to departure, each student selected a disability memoir (e.g., *Gimp*, *Born on a Blue Day*, *The Spirit Catches You and You Fall Down*) to read during the trip. During the last week of the trip, students wrote a four to five page essay in which they briefly described the content of the book; identified and explained the most important theme(s) or critical issue(s) raised by the author; discussed how the major themes or issues related to ideas about disability identity, culture, services, or supports raised during the study abroad; and reflected on personal and/or professional experiences with the issues raised by the book. Eight students' book reviews were offered as data sources.

Also during the last week of the trip, groups created presentations around a theme they identified as important to what they had learned from the study abroad experience. They included stories and information collected during the trip and, in some cases, additional supporting information researched during the final week in Hawaii. The themes chosen by the students included: *poverty; religious beliefs; government structure; disability awareness; and inclusion*. Participating students were represented in each of the five presentations.

### Analyses

Analyses involved multiple rounds of the student-researchers (authors 3-5) and the first two faculty authors reviewing data sources, composing and sharing analytic memos, and discussing emerging themes. In the first round the three student-researchers constructed their post-trip personal essays (Chase, 2011; Ellis & Bochner, 2000) and discussed these with each other and the faculty to refine their ideas. Next, using coding, categorization, and inductive techniques of grounded theory approaches (Corbin & Strauss, 2008), the student-researchers independently reviewed the other students' interviews, journals, book reviews and final presentations to identify ideas of importance to the other students that were similar and different from their own. They met three more times with each other (once) or the faculty (twice) to review and refine their preliminary themes. Next, the student-researchers and faculty independently reviewed the data to confirm, refine, or elaborate the preliminary themes. They then discussed and came to consensus on a final set of themes, a conceptual framework for explaining the students' changing understanding of disability experiences, and illustrative examples. The final step involved a review of the findings by the third faculty member as a check on how well the findings reflected



her own observations of the trip participants and their journal reflections, which she had read during the trip. As needed, her suggestions for clarification were incorporated.

## Findings

The following three sections each begin with a student-researcher's narrative elaborating on the central theme she identified. After each narrative, the theme is extended through conceptually-related examples from other students that illustrate changes in students' understanding of disability and the influence of the study abroad experiences. These central and extended themes include: (1) Cultural importance: Looking across and within cultural processes; (2) Family involvement: Fighting for resources and rights; and (3) Passion for advocacy: Making connections through shared stories. The three student-researchers characterized their personal narrative themes broadly as *discovering*; a concept intended to encompass new knowledge and altered perspectives. Similarly, all students provided evidence of their expanded knowledge of factors affecting the lives of people with disabilities (e.g., religion, poverty, family involvement, human rights, disability acceptance and awareness). Further, students noted how the trip excursions and academic exercises transformed their personal views and professional goals.

### Discovering Cultural Importance

#### *Ashley*

During the trip there was one significant event that really set into motion my discovery of cultural importance throughout the trip. Having never traveled outside of the United States and being raised in a small town my view of the world and culture was limited. Growing up and learning with the same sixty students for the majority of my academic career before college created a narrow perspective in which I understood situations and thought about them. While meeting with the Ghana Federation of the Disabled I had my first moment of cultural shock. We were discussing some families' inability to care for their children with disabilities, which may result in a family leaving their child by the river to be eaten by a snake. Some local traditional beliefs view this as returning the child to the gods. This information was appalling to me, and I was judgmental.

With our class discussion I started to recognize that my knowledge about different customs and environments was limited. When asked by our professors to relate the practice of abandoning a child by the river to something that may occur in America I was unable to even begin such a comparison. Our professors challenged us not to judge these families and we discussed what it must be like to raise children with significant disabilities with very limited resources. Our professors also reminded us that in the United States families that are desperate and are not supported have made decisions such as leaving their child at the local hospital door, admitting them to an institution, killing them, or deciding to abort the child when they get information before birth. In the United States we have the resources and technology to find out before the child is born if they may have a disability. In Ghana it is not very likely that the families will have the opportunity to get such information or have the resources to raise a child with a disability. While these two situations are not completely the same they can be easily compared. They both reflect local beliefs about disability. From this conversation it set me on a journey to look at all situations that we experienced with an open mind. I wanted to understand

why something was the way it was and what was the underlying belief.

Through this trip I was able to recognize how culture can change perspectives. My cultural upbringing has taught me many lessons and values that I may not have realized if I had not been taught to look into them. I now am able to look at a situation and begin to think how culture and values may be impacting what is going on. Learning this key lesson at the beginning of my career journey provided me the tools to look deeper into culture and always recognize it while attempting to “fix” a problem. In the future I want to work in the education system creating a more equal education for all individuals despite any economic or cultural differences they may have. Appreciating and understanding one’s culture and that of others is necessary to build trust and a better future.

### *Looking Across and Within Cultural Processes*

Looking more critically at one’s own cultural assumptions and recognizing variability within and across cultural experiences was a theme expressed by other students as they reflected on the impact of the trip. Summarizing in an interview, a student stated:

“These experiences were memorable because they were so different from my own ideals and perspectives (Ghana), surprising in their simplistic yet complicated issue (Nepal), exemplified the influence people who have a platform have on others (Thailand), the risks some will take for the benefit of others (UAE), and realizing how similar yet different our experiences were from each other on the same trip (Hawaii).”

Students agreed that the structure of the academic assignments supported their learning. For example one noted that:

“Writing journals every week about certain topics helped me not only remember the things I learned but pay attention to detail in the first place, trying to figure out how to relate the information I was learning to one of the various topics we were given to write about weekly.”

Another commented more explicitly about the value of the assignments within the study abroad context as a means of developing cultural awareness:

“These tasks helped to inform my understanding of disability by giving me the opportunity to talk with classmates and professors to hear and learn their perspectives on disability in their own lives and how they processed the experiences we had on our trip. ... It made a great difference that the tasks were performed abroad because we were in the moment at the time and the experiences were fresh in our minds and hearts.”

When reflecting on the dimensions and dynamics of cultural processes, students seemed most surprised by the role of religion. Numerous comments in individual journals and across several final presentations acknowledged the influence of religion in the lives of people with disabilities. They also observed variations in religious beliefs versus practices and the ways that religious perspectives were evolving as old traditions encountered new information. As

summarized in one group's presentation:

“Although religion has a powerful impact on how disabilities are viewed there is variation across each country and within each religion... Before studying abroad, as a group we were unaware of the impact that religion and culture have on the lives of people with disabilities around the world. We have realized that religion is equally as important in the U.S. but it is much more exposed and visible in the aspect of daily life in other countries.”

As an example, the group shared this impact story:

“During our conversations [with individuals at a disability organization] our group members were given a chance to talk with the members about religion in Thailand and received information from three different perspectives. ... There was a variety of religions such as Christian, Muslim, and Buddhist. Each individual experienced their religion differently in society and had unique views on how religion affected their view on disability. [One explained] that while he understands he may have sinned in his past life he does not believe he should be denied supports and rights in his current life. He believes that he is equally as entitled and should use his life to become the best he can be and expand the good within in him. Another member of the Buddhist faith [said] that he did not believe karma was the reason he was in the wheelchair. ... A woman of the Christian faith believed that God is responsible for life and will guide her to something better. She believed life is a mission from God and it is her responsibility to teach empathy. A Muslim family viewed this as a test from God and that you have to help those around you. From this small group of people we were able to see a number of different ways religion is experienced for people with disabilities. ... We recognize that these individuals have found a way to not reject cultural beliefs; [they] keep their beliefs strong while finding an identity within their religion and culture.”

## Discovering Family Involvement

### *Meghan*

As we visited the country of Nepal, I discovered how family involvement and the role of caregivers for people with disabilities are universally vital to the international community of people with disabilities. We visited one place in particular in the Kathmandu Valley, where a couple truly emulated this role. The center provides service and educational opportunities for young children with autism. It was created by a couple, who were initially inspired by their young son who was diagnosed with autism as a toddler. Together, they wanted to create a better life for their child, as well as other children and families experiencing similar situations.

The parents took advantage of their limited resources to establish a place where their child and others with autism could have the opportunity to learn. It was extremely refreshing to see such pro-active and passionate parents in a country such as Nepal where there was such distress. The country had numerous other crucial issues such as the lack of a waste management system and the recent struggle to transition to a democratic government. It was hard for me to

imagine how a family could gather up the resources to provide for the community of people with disabilities. I was inspired because they overcame adversity to provide for their family and others in a country where people with disabilities and their needs are often a low priority. Without question, the family accepted the role of caregiver and understood what that entailed, all while helping other parents like them.

The acceptance of this multi-faceted role is one that is similar to parents and families that I have seen in the United States. I have a twin sister with cerebral palsy, and for the past twenty-two years, my parents have also accepted the complex role of a caregiver for a child with a disability. Through my family and my personal experiences, we have all learned the importance of family involvement. Throughout the trip, one of my initial thoughts in each country was how my sister would live and be treated. I thought about her identity as a person and if she would be seen as a curse or evil. I also thought about the accessibility of each place and her quality of life. As a result of the constant comparison of my sister's life in the United States to the countries we visited, I developed a sense of renewed appreciation for the services and supports available in the United States.

Within the United States, recognition of the rights of people with disabilities has evolved in the past fifty years in ways that some of the countries we visited have just begun. For example, in the U.S. there is an emphasis on seeing people with disabilities as people first; students with disabilities are enrolled in the educational system; and federal medical health insurance is available to many. These concepts and services are more rare in the countries we visited. In many places, people with disabilities struggle for acceptance as people and are still shunned from the public or seen as curses upon their families.

Regardless of the social, education and medical obstacles seen in the other countries, the people and organizations that we had the opportunity to speak with were inspirationally optimistic. They accepted their role of advocates and self-advocates with determination and purpose, and were ready to take on the sometimes seemingly impossible fight of improving the rights of people with disabilities. Going into this trip, I was expecting to learn about other countries and how they viewed disability. I left with a more comprehensive view of not only the countries and their cultures, but how much work it takes to create awareness on a human rights issue. My sister and family have benefited from the hard work advocates, policy makers and people with disabilities have put in to the fight for rights, supports and educational opportunities. Visiting these countries made me appreciate the life my family has created for my siblings, my sister and me.

### *Fighting for Resources and Rights*

Like Meaghan, other students recognized that people with disabilities and their families around the world often find themselves fighting for access to resources, as well as to establish and exercise their rights. Several students observed that individual people with disabilities and family advocates often took the initiative to tackle complex issues, including human rights, despite meager resources. For example, in the presentation on government influences in Nepal, the students stated, "In a political arena wrought with turmoil, disability awareness, supports, service implementation seems a far-off dream. However, with a self-advocacy movement among

the strongest we encountered during our travels, the promise for proper disability supports and services remains hopeful.”

A student who brought prior disability-related knowledge to the trip stated, “I have felt strongly about the importance of disability rights and services for a few years, and the trip just strengthened those beliefs.” Further, students demonstrated an emerging understanding that disability concerns were fundamentally enmeshed with human rights concerns. Looking across the four countries visited, a student wrote:

“In Thailand, I observed many of the same challenges and accomplishments as the three other countries... The challenges included establishing human rights for all people including those with disabilities, and attaining full and effective participation and inclusion of people with disabilities in society.”

Students’ reflections on rights and resources were often linked to comments about a renewed appreciation for what they experienced in the U.S. For example, when reflecting on a conversation with local individuals about rights of women, a student commented, “You always take the rights we have in the United States for granted until you hear a story like that and realize that not everyone treats people like the US does.” However, these appreciations also generated more complex responses that included surfacing critiques of the United States. This became especially clear as students commented on their deeper understanding of the impact of poverty on people with disabilities. In a group presentation on that topic, students noted:

“We observed quality of life for people with disabilities to be influenced by lack of: resources, financial stability, access to medical facilities, and sanitation. After our experiences in these countries we have a new outlook on poverty and disability... [We are] quicker to recognize poverty and disability in the US; [We] realize there can be difference in accessibility of services [even] if [you are] more financially stable in the US.”

Another noted in a book review:

“I appreciate the fact that the United States has more knowledge about disabilities and the fact that we have more acceptance than the countries we have visited, but it also makes me realize how much further we still have in order to achieve all of our goals and spread awareness to everyone in the states.”

Students also recognized that different disabilities were differentially affected by a lack of information and resources. For example, one student reflected:

“One of the key points I took from our site visits was the fact that most mental/intellectual disabilities are not accounted for... The schools [that are] available mainly focus on the physical sense; blind, deaf, physically impaired. Without the ability and resources to recognize these types of disabilities, no help or schooling can be given.”

Discovering Others’ Passion for Advocacy

## *Rachel*

In Ghana, we were introduced to Emmanuel Ofose Yeboah, a strong disability advocate. Emmanuel was born with a physical disability, and although it was customary for families in Ghana to “forget about” their children with disabilities and not care for them. Emmanuel’s mother was different; she wanted her son to have all of the same opportunities as other children. She ensured he could go to school, and when Emmanuel was old enough, he found work on his own. Rather than begging, a typical way of life for many Ghanaians with disabilities, Emmanuel traveled to the capital, Accra, to find meaningful work while still in school. By working, he made enough money to buy his own soccer ball, which was a rarity for children in Ghana. Then, instead of his schoolmates excluding him from playing with them, he controlled the game. As Emmanuel got older, he worked to raise awareness about disability by riding a bike across Ghana with one leg. This turned Emmanuel into a celebrity in Ghana, and later into a celebrity in the United States. The Challenged Athletes Foundation in San Francisco heard Emmanuel’s story and brought him to the United States. While he was here, they provided him with surgery for a prosthetic leg. He returned to Ghana with a renewed sense of advocacy and has worked to help people obtain wheelchairs and other necessary devices. Additionally, the documentary Emmanuel’s Gift was produced to tell his story, he has won an ESPY award from ESPN, and he has even become friends with Oprah! Emmanuel recently started construction on a school for students with disabilities in Ghana. His story shows that even with few resources, one can make great things happen, which was echoed throughout the trip.

Although we visited many organizations there were three that really stuck out to me. First, in Dubai, we visited a nursery school started by two energetic, ambitious young women who had a vision of a school for children of all abilities because no such place existed in Dubai despite supporting legislation. We visited them the week before they opened their doors, and it was remarkable to see all of the hard work and dedication that they poured into the school even in the face of some local resistance. The second notable visit for me, because of my prior experiences with vocational programs, was the Technical & Skill Development Centre for the Blind & Disabled in Nepal. They provide training in areas such as computers, office management and English language, art and clay work, chalk and candle-making, knitting, tailoring, mobile telephone repair, and weaving. They also have an early intervention program and health and physiotherapy. In addition, they have an internship program that looked remarkably similar to an employment project that I worked at in the US. The Centre trains students in job areas, provides certification, finds them an internship/job, and then helps the student sustain themselves past the program. It was really interesting to see familiar concepts applied halfway across the world. Our visit to Ratchasuda College at Mahidol University in Thailand was also a significant visit for me, because I am very interested in school to adult life transitions, and especially access to higher education for students with disabilities. This interest has grown out of observing the experiences of friends with disabilities as well as the positive effects that college has had on my own life. Ratchasuda College was started in 1993 specifically for students with disabilities, especially those with hearing impairments. The dean of the college gave us an overview of the program as well as the currently disability situation in Thailand. Although there were separate programs in the college for students with disabilities, it was integrated within the larger university, and the courses were very accommodating to students

with disabilities.

One of the most remarkable things about the trip was the energy, enthusiasm, and dedication of everyone we met. People were excited to meet us and teach us about what they do in their country. Also, they were eager to learn from us about what we do in the US. Similar to our country, there are strong advocates who are looking for equal protections. Although our country still has much room for growth, they admired our progress, and wanted to learn from us. Their undying passion to advocate for, teach, and support people with disabilities, as well as the desire to learn more about best practices, showed me that some of the rights we have here in the US are taken for granted. The mutual respect, understanding, and knowledge shared among our group and the people that we met was more of an education for me than anything I've learned here in Delaware. After our trip, I had a renewed perspective on disability rights. I also came back more confident in my goal of working in disability policy. A year before the trip, I declared a minor in political science. I knew that working in policy would have broader implications for people with disabilities in America. However, I saw this first hand in other countries, by seeing how limited and restricted people were by the policies in their countries. However, what they all had in common was that they did not let this stop them. I came back to the US knowing that it is possible for all of us to make a difference. Upon returning, I sought out an internship in Washington, D.C. to further my own knowledge and understanding of domestic disability policy to apply my education to our society. After graduating, I hope to eventually work in policymaking, and hope to one day travel again and share more information with countries around the world.

### *Making Connections Through Shared Stories*

Interacting with disability advocates in multiple contexts and hearing advocates' stories in their own voices had a strong impact on the students as they reflected on their personal views and professional goals. As one student stated:

“[Visiting organizations and talking to people with disabilities] was monumental in my new understanding. The personal stories and explanations we heard from the people who lived in these countries were inspiring and informative. I know that being able to personalize the issue made all the difference. It was truly special to interact with these people.”

In some cases, these personal stories, while “inspiring,” also up-ended students' expectations about how the world worked. For example, a student noted in a journal, “Although there seems to be many struggles in the lives of people with disabilities in Nepal, to my surprise there were many advocates who displayed extraordinary passion towards obtaining services and support.” Learning about advocates' personal experiences and observing new or alternative ways people with disabilities were improving their own lives seemed to help students gain more nuanced insights into the nature of disability advocacy. One commented, “These experiences were where the most was learned because the political and personal viewpoints came together. Actual people were providing insight on the policies and gave us a firsthand look on how families used their resources available.” One student also commented on the value of speaking with multiple individuals and groups in each country, “The impact here is that we learned that

we cannot take one source's information for granted but look at many different sources and compare and contrast them because different people in different positions have varied responses to the similar situations.”

Connecting through personal stories prompted several students to make a shift in how they thought about disability. One who had no prior personal or academic experiences with disability stated, “[The trip] has had an impact, I no longer use the word retarded, and I correct people when they use it. I look at my surroundings every day and note whether it is handicap accessible or not.” Another student's book review concluded with, “As Emmanuel Ofose Yeboah's friend says, “It's not about thinking ‘Oh man, I am glad that I do not have a disability like him; it's about thinking, ‘Oh man, I wish I could be more like him [referring to Emmanuel and others who have disabilities].”

Throughout the trip several students commented on the allure of an “around the world” trip, the possibility of returning to the visited locations as professionals, and the impact on their professional knowledge and goals. In a later interview, one student stated, “This trip helped me realize that living/working abroad is something I would like to do in the near future... I am interested in traveling back to one of the countries visited and put my [future graduate] degree to use...” Some reported a shift in their understanding of their “needs”, such as one student's commentary that, “The entire experience was meaningful and humbling to me having to live out of a 15 lb suitcase. It really made me understand how to use only the essentials.” Another student reflected:

“I was initially drawn to this trip because I wanted to travel the world while learning and experiencing cultures that I otherwise would not have the opportunity to travel to. After looking further into the trip I realized it was a great opportunity for me, as a nursing student, to develop an understanding of global healthcare issues and available services.”

Another stated:

“[The trip] made me realize how important having an understanding of disabilities is. I babysit for a girl with a disability and I often think about how difficult her life would be in some of these countries. I am very interested in health care and this has really made me realize how I want to continue in the health care field and work with people with disabilities.”

## Discussion

Through this “around the world” trip, students were challenged to think critically about their cultural assumptions and understanding of disability. The comparative nature of the experience supported them to more directly confront the influence of factors that had previously been less visible to them, such as the role of religious beliefs and poverty. For several students, this led to an emerging recognition of connections among disability issues and larger human rights issues, an appreciation for the resources and rights they had, and an acknowledgement that progress on disability issues was still needed in the U.S. as well as other countries. In some cases this recognition sparked or confirmed a desire to make a contribution to the disability field at



home or abroad through their future professions or personal lives. Students agreed that seeing each country and meeting people through planned academic and cultural excursions, as well as their own informal forays, were instrumental to their academic and personal growth.

Having limited or no prior experience with disability issues did not seem to create major barriers to learning for students. The opportunities to meet many different people with disabilities, their families, and other advocates coupled with the background readings and regular class discussions made the information accessible to students regardless of prior knowledge or major. Students typically reported gaining some insight into individual and family experiences of disability as well as a variety of approaches to services and supports for people with disabilities.

The comparative approach assisted students to observe variability across experiences. However, students did require guidance from faculty during class discussions to push beyond simplistic comparisons of the most readily observable cultural differences. Two aspects of the students' reflective work seemed most critical. First, students benefited from the structured opportunities that were embedded in journaling and class discussions to consider how their own beliefs and experiences differentially influenced what they noticed and counted as learning. Second, personally engaging with multiple people and organizations within each country and then examining the variability of personal experiences within and across contexts helped students to develop more nuanced views of culture and disability.

We believe that the trip would have been enhanced if U.S. college students or an instructor with disabilities had joined the group. They may have offered additional insights into disability as a cultural phenomenon. However, the lack of physical accessibility and difficult terrain in several places we visited would have required in some instances an alternate itinerary and, in all cases, strong contingency planning with knowledgeable individuals residing in each locale (Mobility International USA, n.d.). Even with the advance communications done for this trip, the reality on the ground was often not what had been arranged. For example, in one location upon arriving late at night after a long flight, we learned that drinking water and other beverages were not available in the airport nor would any be available at the place we spent the night until a small restaurant opened for breakfast -- despite assurances to the contrary before our departure. Likewise, narrow city streets with gutters, no sidewalks, and heavy unregulated pedestrian, cart, and car traffic made navigating some streets a harrowing adventure under the best of circumstances. The participating students readily recognized the accessibility issues such circumstances presented. Accessibility itself could serve as the core of a problem-based learning approach in future disability-focused study abroad trips.

## Conclusion

In summary, this unique and challenging study abroad program met general learning goals for short term programs by making a positive impact on students' knowledge, attitudes and confidence. The program also accomplished a more specific disability studies pedagogy goal of supporting students to view disability from alternative perspectives. This was facilitated through encounters with people and organizations that highlighted cultural variations and afforded opportunities to forge personally meaningful connections to cross-cutting social issues. Within the framework of structured academic reflections, those connections became the impetus for students to identify personal change themes similar to those identified in service-learning study

abroad programs (Gaines-Hanks & Grayman, 2009) and by students with disabilities themselves (Shames & Alden, 2005; Scheib, 2006). Students reported wanting to take action to use what they had learned to make a difference, whether that was through undertaking a disability-related policy internship, changing the language they used when talking with others about disability, or expanding their professional practices to more specifically address disability. Although we were unable through this study to follow the students post-graduation to determine what actions they actually took, this disability-focused study abroad experience produced a fundamental shift in their knowledge and attitudes, “critical progress” that should serve as a foundation for those future actions.

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# Stigma or Empowerment? What Do Disabled People Say About Their Representation In News and Entertainment Media?

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**Abstract:** This paper asked people who identify themselves as disabled to evaluate the American media's presentation of disability. Disabled people internationally took an online survey on media representations. Respondents (N=390) say much of the American film, TV, and news representations of disabled people are problematic and disempowering.

**Key Words:** news, entertainment TV, film

Much content analysis for the past 30 years and more has revealed problematic media representations of disabled people and their concerns. Only a few media researchers have asked disabled people themselves what they think of media representations of their community or issues (Wilde, 2010, 2007; Pakman, 2008; Sancho, 2003). This survey of people who identify as disabled attempts to fill that void.

In the summer of 2010, an online survey of disabled people from around the world was taken to find out what disabled people think about their representation by the news and entertainment media. However, because the authors of this article are U.S.-based, primarily U.S. disability organizations were contacted to have their members take the survey. Several international disability organizations did send out the survey link, so survey respondents represented 18 countries (N=390). Although admittedly U.S.A.-centric, the disability issues and entertainment media evaluated in the survey are available in countries that have access to Hollywood films and TV, as they are available in many countries around the world, as well as online. The U.S. mainstream film industry alone releases 500-600 films each year, many of which are exported internationally (Motion Picture Association of America, 2011).

This survey is grounded in disability theory that examines dominant cultural discourses about disability to assess ableism or stigma within a variety of cultural representations, which could lead to the social oppression of people with disabilities (Garland-Thomson, 1997, 2011; Wendell, 1996; Makas, 1993). Disabled people receive messages about society's expectations of them through mass media representations such the Supercrip narrative, which tells them to "overcome" a disabling condition, or to seek "cures" as in the Medical Model (Nelson, 2011; Haller, 2010; Titchkosky, 2008; Garland-Thomson, R. 2002; Hardin, Hardin, Lynn, & Walsdorf, 2001).

## Media Content and Disability

Mass communication scholars have long known that media frames are imbued with cultural meanings. This knowledge is especially important when considering a social group like disabled people because they still experience many architectural, occupational, educational, and communication barriers that keep them from being able to fully participate within society. Therefore, film, TV, advertising, and news images still provide many of the cultural representations of disability in many countries. A ground-breaking poll in 1991 assessed

Americans' attitudes toward disability after the passage of the 1990 Americans with Disabilities Act (ADA). The poll showed that Americans surveyed were less likely to feel awkward around disabled people after having viewed fictional television and movie presentations about disabled people (Louis Harris, 1991). These surveyed Americans were relying on information about the disability experience from mass media to form their views. Although surveys of the U.S. disability community have been done (National Organization on Disability, 2010), none have asked disabled people about their opinion of news and entertainment portrayals of their social group. In honor of the 20<sup>th</sup> anniversary of the ADA, the National Organization on Disability (NOD) surveyed the U.S. disability community. The NOD president Carol Glazer said:

“The disability rights movement lags behind other civil rights movements and we have to catch up. There is a role for everyone. Governments need to remove disincentives for disabled people so they can start to work. Businesses need to realize the enormous contributions workers with disabilities can make. Schools need to prepare students with disabilities sooner for the world of work. And Hollywood should routinely feature more disabled people in their TV shows and movies (NOD, 2010).”

It is these inequities in cultural representations from Hollywood TV and film producers that inform this research project – What do people who identify as disabled and who actively embrace disability rights think about film and TV representations of disability?

Kathryn Montgomery in *Targeting Prime Time* (1989) argues that advocacy groups, such as those for the disability community, are extremely concerned with their mass media depictions because of their potential to culturally demean them. She writes:

“To minorities, women, gays, seniors, and the disabled, television is a cultural mirror, which has failed to reflect their image accurately. To be absent from prime time, to be marginally included in it, or to be treated badly by it are seen as serious threats to their rights as citizens (p. 8).”

In line with this, Dillon, Byrd, and Byrd perceived television as an instrument to change attitudes toward disabled people. They concluded that prime time television portrayal of disability might be more realistic if it could consistently integrate persons with disabilities into everything from news to sitcoms to talk shows (1980).

Government policies influence the disability rights movements. In the United States, for example, federal officials approved the early disability rights legislation, but it wasn't enforced, giving the message that this community's rights weren't truly important. These power elites in the U.S. government helped frame disability rights in its early days. Research by Olien, Tichenor, and Donohue (1989) found in news stories about conflict that the power elite helps form the media position, so the news media end up reinforcing the outlook of those who hold dominant power.

These problems of news misrepresentation and federal government framing affect the news coverage of disability issues because research has shown how the media often report on disability as a medical or social welfare problem (Clogston, 1990). In fact, Joe Shapiro, who

wrote a book on U.S. disability rights history (1994), reports that the disability lobbyists for the ADA made little use of the media to push their ideas because they thought the media stories would continue to perpetuate stereotypes and hinder the public's understanding of disability rights (1993). For example, the disability community has long complained about one particular representation in the media – The Supercrip. George Covington (1988) believes it has been around since U.S. newspapers' penny press days. Ground-breaking news media and disability researcher John Clogston defined a Supercrip as the following: the disabled person is portrayed as deviant because of "superhuman" feats (i.e. ocean sailing blind man) or as "special" because they live regular lives "in spite of" disability (i.e. deaf high school student who plays softball). This role reinforces the idea that disabled people are deviant– that the person's accomplishments are “amazing” for someone who is less than complete (Clogston, 1993). Covington explains how the news media's Supercrip stories cause problems:

“Too often, the news media treat a disabled individual who has attained success in his field or profession as though he were one of a kind. While this one-of-a-kind aspect might make for a better story angle, it perpetuates in the mind of the general public how rare it is for the disabled person to succeed (1988, p. 1).”

In addition, Laura Mitchell asserts that the U.S. press misses important stories related to disabled persons because of their persistence in portraying them as inspirational "SuperCrips" or "helpless victims." Mitchell explains:

“The press misses the boat largely because of a narrow view that pigeonholes disabled people and makes subconscious assumptions about who we are and what we do. . . . Insensitivity and stubborn ignorance characterize much press coverage of disability-related stories (1989, p. 19).”

Even in 2012, journalists still use the inspirational Supercrip image because they know that's what their news directors, editors, and audiences want.

In addition to the Supercrip news representation, other news media models of disability representation have also been identified from a seminal study of more than a dozen major U.S. newspapers (Clogston, 1990) and a 1995 content analysis of the media coverage of the Americans with Disabilities Act (Haller, 1999). These models of the news media representation of disability fit into either a traditional (stigmatizing) or progressive (empowering) category, although setting up this kind of dichotomy is understood as problematic. In applying the models to post-ADA news content, Haller's 1995 analysis did not force news stories into one category or another. A single news story may represent several models, and the headline (not written by the journalist) may reflect another model completely. In this survey, participants were allowed to select all models, if they felt all are represented in the mass media.

Clogston's traditional categories (1990) include the Medical Model, the Social Pathology Model, and the Supercrip Model. The Medical Model presents disability as an illness or malfunction and persons with disabilities as dependent on health professionals for cures or maintenance. The Social Pathology Model presents disabled people as disadvantaged and economically dependent on the state or society, and the support is considered a gift, not a right.

The Business Model, Haller's added traditional category model, presents people and their issues as costly to society and businesses especially. Making society accessible for people with disabilities is seen as not worth the cost and as a burden to businesses, i.e. accessibility is not profitable (Haller, 1999).

Clogston's progressive categories include the Minority/Civil Rights Model and the Cultural Pluralism Model. The Minority/Civil Rights Model portrays people with disabilities as members of the disability community, which has legitimate, political grievances. In this model, people with disabilities have civil rights to fight for, just like other groups, and accessibility to society is a civil right. The Cultural Pluralism Model presents people with disabilities as multifaceted, and their disabilities do not receive undue attention. These people are portrayed in way that people without disabilities would be.

Haller added two progressive models: the Legal Model and Consumer Model (1999). In the Legal Model, the media explains that treating disabled people in certain ways is illegal. The Americans with Disabilities Act and other laws are presented as legal tools to halt discrimination. The Consumer Model portrays people with disabilities as an untapped consumer group and reasons that businesses and society in general could profit from making society more accessible. If people with disabilities have access to jobs, they will have more disposable income and less need for government assistance. However, many times this empowering news representation does not appear in the media because journalists' predominant understanding of disabled people still resides in the Medical, Business and Supercrip Models (Haller, 2010).

Many of these media models can be tied to the attitudes and assumptions U.S. society has about people with disabilities. Legal disability studies Paul Miller connects some of these societal attitudes to people's fear of becoming people with disabilities themselves: "This fear is based on the notion that a disabled person's life is inferior to, and less precious than, an able-bodied person's life" (1993). These fears lead people to seek out stories of Supercrips, so they can "take comfort" and feel hope from the fact that Supercrips succeed "in spite of" a disability. The news media know their audiences and what they like and give it to them by making many stories about disability fit the Supercrip model. Even high school journalists know this is what the public wants, according to Laura Miller, whose survey of high school journalism students found that the majority of the students said they "would treat a person's disability as a news oddity, worthy of top placement in a news story" (1995). Interestingly, the students all had positive attitudes toward people with disabilities, but in terms of their news values, they had not been sensitized about non-stigmatizing ways to present people with disabilities.

Many of the news media stories about disability today are still similar to those criticized by Biklen in 1987: Reporters "typically cast in terms of tragedy, of charity and its attendant emotion, pity, or of struggle and accomplishment" (p. 81). Biklen found that the themes of news stories had become predictable as they focused on the angles of inspiration and courage.

#### Entertainment TV and Film and Disability

Many of the same stigmatizing media models also apply in entertainment TV and films. Those stigmatizing images have been in popular literature for centuries before TV and film



existed. U.S. news media and disability researcher Jack Nelson (1994) explained two media images that come from popular fiction: the Tiny Tim-like character as a “sad, unlucky disabled person in need of pity and charity” and the Supercrip as a “courageous disabled person, celebrated for overcoming a disability and performing seemingly superhuman feats” (p. 59). UK disabled writer and activist Paul Hunt identified 10 common stereotypes of people with disabilities in media:

“1. The disabled person as pitiable or pathetic. 2. An object of curiosity or violence. 3. Sinister or evil. 4. The super cripple. 5. As atmosphere. 6. Laughable. 7. His/her own worst enemy. 8. As a burden. 9. As Non-sexual. 10. Being unable to participate in daily life (1991, pp. 46-47).”

Disability studies scholar Tom Shakespeare (1999) says these inaccurate stereotypes are dangerous because they “reinforce negative attitudes towards disabled people, and ignorance about the nature of disability” (1999, p. 166).

However, some scholars believe that wishing for the absence of negative stereotypes of disability in the media is the wrong direction to take. Wilde (2010) conducted focus groups with a variety of people with and without disabilities in the United Kingdom, asking them about soap opera representations of disability. She says, “portrayals of disability contributed very little to the cultural capital of any of these participants, having little or no value as a resource for collective or self-identity, providing little pleasure and reassurances of fears.” Wilde believes that trying to have the media avoid stereotypes may lead to fewer characters with disabilities in media narratives:

“Disabled characters should float freely between stereotypes and multiple roles, interwoven on all narrative roles, just as non-disabled people do. Our place within media narratives should be everywhere, affording us the same range of stereotypes as non-disabled people, as angels, heroes, villains, and so on (2010).”

The disability community has long advocated for more diverse and complex disabled characters in films and TV; preferably played by disabled actors (Gilman, 2013). However, there are still so few non-stigmatizing narratives in the media to counter the negative stereotypes of disability, which many viewers could arguably believe. It is feared that the tired clichés would win out.

Progress in the variety of U.S. media narratives about disability is occurring a bit, because entertainment TV and film is more audience- and advertising-driven. In 2000, a U.S. cartoon show featured a wheelchair-using 8<sup>th</sup> grader, Pelswick, as the main character of the show of the same name. Created by quadriplegic cartoonist John Callahan, the Pelswick character illustrates how some TV images of disabled people are shifting to more equal and mainstream representations and some Hollywood production teams are learning to diversify representations (Haller, 2010). A number of animated shows on U.S. TV have characters with disabilities. Even though people with disabilities do not appear to participate in the creation of the shows, the storylines demonstrate knowledge of disability issues. For example, *South Park* on Comedy Central, *Family Guy* on Fox, and *Rick and Steve Happiest Gay Couple* on Logo all have main or

recurring characters with disabilities, and people with disabilities praise these characters because they subvert the usual disability stereotypes (Mallet, 2007). Other countries are following this lead. Ireland launched an animated series starring a girl with Down syndrome, which is voiced by a woman with Down syndrome, Aimee Richardson (Down Syndrome Daily, 2011). In New Zealand, its Ministry of Social Development is funding the Unique Extras agency, which hopes to place actors and models with disabilities on television (Powley, 2012).

For example, *South Park*, the irreverent animated show featuring four foul-mouthed primary-school boys, occasionally spotlights their schoolmate Timmy, a wheelchair user with garbled speech. Timmy was voted "The Greatest Disabled TV Character" in a poll by BBC's Ouch! Jimmy, who uses crutches, is another disabled character who sometimes teams with Timmy. The U.S. disability magazine *New Mobility* reports on the popularity of Timmy among disabled voters at BBC Ouch!:

“With his jagged teeth and can-do spirit, Timmy appears at first glance to uphold the condescending disability stereotypes that are gradually fading from mainstream entertainment. But like everything else in *South Park*, he's actually challenging preconceptions, toppling taboos, and weaving his uniqueness into the fabric of the show (Shannon, 2005).”

Ouch! said Timmy got the vote because of his “badass” activities on the show, including being lead singer of Timmy and the Lords of the Underworld, joining the notorious “Krips” street gang, and being at the center of a *South Park*'s debate over “Do the handicapped go to heaven?” (Shannon, 2005). Mallett (2007) explains that *South Park* resonates because it “satirizes struggles over ontological categories.”

Disability on network TV in the United States received more visibility in 2004 when Josh Blue, a comedian with cerebral palsy, won the NBC network's *Last Comic Standing*. Physical difference depicted on reality shows illustrates that it has staying power with the development of *Little People, Big World* on the channel TLC in 2006. The reality show follows the lives of the Roloff family, which has two parents and one son who are little people and three children who are average-sized. The show focuses on the father Matt, an entrepreneur and little people advocate who has diastrophic dysplasia, and mother Amy, a preschool teacher who has achondroplasia, as they live their lives with their four children on their small farm in Oregon. TLC says that *LPBW* is “the most comprehensive television documentary ever about the lives of little people” (Lee, 2006).

The show, which ended its sixth season in 2010, has received high ratings for TLC (Crupi, 2006). However, although most praise the show for its matter-of-fact portrayal of little people's lives, some little people advocates worry that it may encourage voyeurism. Dan Kennedy, the father of an LP daughter, writes, “Every little person is intimately familiar with the supremely unpleasant experience of being the subject of scrutiny. *Little People, Big World* lets viewers satisfy the need to stare: It's voyeurism without the fear of being caught” (2006, March 24).

Hollywood films have had the same mixed history of both stigmatizing and empowering content. While the disability community despised the 2001 film *Million Dollar Baby* for its depiction of assisted suicide for the main character when she gains a disability, and the disability community loved the 1986 film *Children of a Lesser God*, which netted the first Academy Award to a deaf actor (Haller, 2010). Disability images have experienced ups and downs in Hollywood in recent years because it could not seem to let go of stigmatizing stereotypes, even when it also embraces empowering filmic narratives that depict more realistic disability experiences.

A number of film and disability studies scholars have critiqued many of those clichéd, stigmatizing, or negative images of people with disabilities over the years (Enns & Smit, 2001; Longmore, 1987;; Norden, 1995; Whittington-Walsh, 2002;). In fact, one disability and film studies scholar began a research agenda into film depictions because he saw little resemblance between actual people with disabilities and the characters with disabilities in the movies (Norden, 2001). Also, some disability studies scholars now acknowledge the power of inaccurate or stigmatizing film images to add to the oppression of people with disabilities. UK disability studies scholar Colin Barnes says that the social model of disability's notion of society's barriers causing "a disabling environment and culture" also includes film images. They lead to "the devaluing of disabled people through negative images in the media – films, television and newspapers" (2003). This history of negative media stereotypes of disability has hampered the disability community's interaction with media, and it was therefore crucial to survey people who identify as having disabilities on their current opinions about the media.

## Methodology

The survey was developed and pre-tested in the spring of 2010, after the review of several other surveys of people with disabilities (Pakman, 2008; Special Olympics, 2003; Hahn & Belt, 2004) and the literature about media attention and disability issues (Haller, 2010). The survey enables people with disabilities to identify themselves as such. We wanted the survey to include all individuals who identify as having impairment(s) and/or disabilities, but we did not force them to choose one monolithic definition as Siebers argues for a "complex embodiment" that recognizes the differences among people with disabilities (2008).

### Data Collection

The respondents in this study were people with disabilities around the world. However, as noted, many more U.S. people with disabilities were contacted to take the survey. Initially, this survey included people with disabilities only in North America about U.S. media. However, because it was accessible online, we opened it up to anyone worldwide who wanted to take it. We contacted potential respondents by sending the survey link to people at 31 U.S. and Canadian disability-related organizations or groups as well as at least two officers at all 50 U.S. Independent Living Centers. A few of the groups are the Down Syndrome Association of Los Angeles, Disability Rights Education & Defense Fund in California, Disability Rights Promotion International in Canada, and the Disability Studies in the Humanities listserve, which has members worldwide. The survey also did ask identity-related questions, but those are not explored in this article. Due to the promotion of the survey to disability-specific groups, participants who did not identify as having a disability probably did not take the survey, and the

few people without disabilities who took the survey may have been acquaintances or family of people with disabilities who received the link to the survey. Another limitation of the survey was that someone with an intellectual disability may have needed assistance in taking the survey; the researchers would have provided that assistance, but were not contacted. Researchers did provide assistance to several visually impaired respondents, whose screen readers could not access the survey. With these limitations, the respondents skewed toward those with physical, mental health, vision or hearing-related impairments.

As this was an online survey, we followed a convenience sample approach to ensure that the respondents were chosen on the basis of their affiliation with disability organizations and their listserves and email communications. The data were collected through Survey Monkey, a survey website, which was programmed to avoid multiple responses from the same individual participant. The respondents were assured of the confidentiality of both respondent and organization identities.

A total of 430 respondents started the survey, and 359 completed the survey with a response rate approximately 83.5%. Among 430 respondents, 390 were people with disabilities. 29.7% (n=116) of them were born with disabilities, while 70.3% (n=274) of them acquired the disabilities later. For the current study, we analyzed the data of only the respondents who identified themselves as having disabilities.

Among the 390 respondents, the average age was 47.31 ( $SD = 13.91$ ), ranging from 18 to 82 years old. Males made up 26.7% (n=104) of the respondents, 52.6% (n = 205) of the respondents were female, and 81 respondents did not identify their sex (20.7%). Participants represented a variety of races and ethnicities, but the majority were Caucasians (66.9%, n=261), followed by respondents of African descent (3.8%, n=15). People who identified themselves as having two or more ethnicities represented 3.1% (n=12) of the respondents; 1.5% (n=6) of the respondents were of Asian descent. Additionally, 1.3% (n=5) of the respondents were of Hispanic and/or Latino descent; 0.8% (n=3) were American Indians and/or Alaska Natives, and 0.5% (n=2) were Native Hawaiians and/or Other Pacific Islanders. Eighty cases (20.5%) did not disclose their ethnicities.

The 390 respondents in the current study were from 18 countries. The U.S. respondents represented 65.4% (n=255) of the respondents, followed by 5.6% (n=22) of the respondents from Canada. Another 1.3% (n=5) of the respondents reported that they were from the United Kingdom, 0.8% (n=3) were from Germany, and 0.5% (n=2) were from Australia and Vietnam respectively. These twelve countries each had only one respondent participating in this study: Albania, Costa Rica, France, Iran, Ireland, Jamaica, Japan, Kenya, Mexico, New Zealand, Nigeria, and Sweden.

Many types of disabilities were represented among the respondents. The listed disabilities that had no responses were people with Down syndrome and people with HIV or AIDS. The most represented disabilities were wheelchair use, arthritis, polio, cane users, those with depression or anxiety disorders, allergies and asthma, visual impairments and/or blindness, back injuries and cerebral palsy. Respondents could report multiple disabilities on the survey.

## Limitations

The study had limitations with the research and sampling methods. First, the survey research of the media forces respondents to select from predetermined categories and cannot explore *how* the respondents watch or read the media. Therefore, the current study cannot detect why people with disabilities perceive media representations as unrealistic or negative or how they would like themselves to be fairly portrayed by mass media. Second, survey research can test only correlation. Because of the correlational nature of the surveys, we cannot identify any causal relationships between any of the variables tested. Third, we used a convenience sampling instead of random sampling method, and doing so affected the generalizability of the findings across the target population world-wide. Although a convenience sample is never ideal, we argue this was an acceptable sample, considering the difficulty of acquiring a complete frame list of all the people with disabilities.

## Measures

Respondents indicated the extent to which they agree or disagree with the following statements about the media's representation of disability issues on a scale of 1 (strongly disagree) to 7 (strongly agree).

### Perceived realism:

- In general, mass media accurately portray the lives of disabled people.
- In general, mass media provide objective information for the public to learn about people with disabilities.
- In general, mass media gives enough coverage about disability issues.
- In general, mass media's representation of disabled people reflects how they are in real life.

The Cronbach's alpha for this index was .889.

Medical model: "In most news stories you read about disability issues, disability is presented as an illness dependent on health professionals for cures or maintenance."

Social pathology model: "In most news stories you read about disability issues, disabled people are presented as disadvantaged who must look to the state or to society for economic support, which is considered a gift, not a right."

Supercrip model: "In most news stories you read about disability issues, disabled people are portrayed as superhuman, inspirational, or 'special' because they live with a disability."

Business model: "In most news stories you read about disability issues, disabled people and their issues are presented as expensive and costly to society and business especially."

Minority/Civil rights model: "In most news stories you read about disability issues, disabled people are presented as members of a 'community' or social group, which is deserving of civil rights."

Legal model: “In most news stories you read about disability issues, disabled people are presented as having legal rights, in which they may need to sue to guarantee those rights.”

Cultural pluralism model: “In most news stories you read about disability issues, disabled people or their issues are portrayed as able-bodied people would be, as a multifaceted people whose disabilities do not receive undue attention.”

## Results

The overarching research question was, how do people who identify as disabled evaluate the American media’s presentation of disability? This is a broad question. To better capture people with disabilities’ opinions on media representation of disability, we asked the respondents to evaluate American film and TV programs’ representation of people with disabilities, news media’s coverage of disability issues, and the overall media representation of people with disabilities.

We asked the respondents to evaluate 38 recent American film or TV programs, such as the 2009 movie *Adam* and the TV shows *House*, *Lost*, and *South Park*. Among all the programs evaluated, the top five programs that were most viewed by people with disabilities were *Extreme Home Makeover* (75%), *House* (62%), *Finding Nemo* (62%), *Little People, Big World* (62%), and *Monk* (59.2%). On the 1-7 survey scale of stigmatizing to empowering, all 5 were closer to the empowering end of the scale, with *Little People, Big World* being viewed as the most empowering. See Table 1.

We asked the respondents to evaluate 16 relatively older American TV programs and films, such as *Frida* (2002), *Sesame Street* (1969-present), and *The Station Agent* (2003). The top five older programs and films that were most viewed by people with disabilities were *Rain Man* (86.4%), *A Beautiful Mind* (77%), *Sesame Street* (77%), *Dumb and Dumber* (68.2%), and *Children of a Lesser God* (59.5%). All these entertainment programs, except for *Dumb and Dumber*, were seen as empowering. Interestingly, *A Beautiful Mind*, *Sesame Street*, and *Children of a Lesser God* all scored as having even more empowering representations than *Little People, Big World*. *Dumb and Dumber* was viewed as highly stigmatizing people with disabilities. See Table 2.

The respondents also evaluated the news media coverage of 68 disability issues, which were selected based on a content analysis study by Haller (2003). The issues’ topics included health care access, access to legal services, Medicare funding, special education segregation, and voting access. On a scale from 1 (minimum/poor coverage) to 7 (enough/balanced coverage), respondents say that American news media poorly cover disability issues. Only two issues, autism and the Terri Schiavo case, received a rating of 4 or above, indicating enough coverage.

The results suggest the disabled survey respondents perceive that the news media don’t give enough or balanced coverage to most disability issues overall. Only 8 disability issues scored a 3, meaning they were seen as being covered a small amount. They were AIDS/HIV, the Americans with Disabilities Act (ADA), assisted suicide/euthanasia, blindness issues, children

with disabilities, closed captioning - access to TV/Internet content, disabled veterans issues, and health care access and costs. Other questions asked about general evaluation of representations in entertainment and news media, and most respondents reported that the news media do not cover disability issues enough, present the “real life” experiences of people with disabilities, or accurately present people with disabilities in entertainment programs. Also, the majority of the respondents preferred that disabled actors play disabled characters. In the area of online media, respondents indicated they are embracing some forms more than others. Most have Facebook pages (68%), but only 12-13% have disability related websites or blogs.

The study also asked the respondents to assess the media’s overall representation of people with disabilities in general. On a scale from 1 to 7 (1 means not realistic at all and 7 means very realistic), the respondents indicated that the media’s overall representations of people with disabilities were not realistic ( $M=1.95$ ,  $SD = 1.08$ ). We also asked the respondents to rate how news media frame disability issues in general. The most prevalent frames they reported were ones considered more stigmatizing (the Medical model, the Social Pathology model, the Supercrip model, and the Business model). The respondents said they did not think the news media frame disability using progressive models (Minority/Civil Rights model, the Legal model, and the Cultural Pluralism model). See Table 3 for the means.

## Discussion

The survey results illustrate what some people who identify themselves as people with disabilities think about their representation in U.S. news and entertainment media. The survey aimed to provide information that disability advocates can use to open a discussion with U.S. media producers and journalists about the problems with the disability representations within news and entertainment media.

Some of the results clearly match previous content studies of media. Only 31% of survey respondents reported being interviewed by the news media. A content analysis in 2002 found that only about 30% of U.S. news stories had a person with a disability or disability organization as a source (Haller, 2003).

Interestingly, but not unexpectedly, the survey respondents had not seen many of the more recent entertainment media with disability content, as current media have much more options ever, with as many as 800 cable TV channels in 2010 in the United States, and Hollywood releases more films each year – 206 films were released in 1988 as compared to 633 in 2008 (The-numbers.com, 2010). In addition, the average age of respondents skewed older at 47; this age group is sometimes viewed as being busy with job and family and may have less time for media consumption.

Another reason respondents viewed older media more often and found them to be more empowering may be because of the content itself. Some of “the firsts” happened in that older entertainment media – for example, *Children of a Lesser God* (1986) was the first time a deaf actor starred as the main character in a major Hollywood film. The 1988 movie *Rain Man* was the first major Hollywood film to address the topic of autism with big-name actors – Dustin Hoffman and Tom Cruise. The TV show *Sesame Street* has always been ground-breaking for its

diverse and inclusive cast. In 1993, the children's show added a 9-year-old girl, Tarah Lynn Schaffer, who used a wheelchair because of osteogenesis imperfecta (Duckett, 1993).

In addition, many current media programs with disability content are somewhat of a "mixed bag" in terms of representation. For example, the TV show *Glee*, which began on U.S. TV in 2009, has drawn controversy for casting a non-disabled actor to play its wheelchair-using main character (Davis, 2009). On the other hand, it has been praised for hiring an actress with Down syndrome to play a continuing character on the show (Dean, 2010).

Finally, older entertainment media and news coverage were broadcasted during a time when disability rights were gaining traction in U.S. society, and the media took notice (Covington, 1988). Major laws passed such as the Rehabilitation Act in 1973, which outlawed discrimination at any place that receives federal money, and the Americans with Disabilities Act in 1990, which tried to combat discrimination against people with disabilities in all aspects of U.S. society. In the late 1970s, the U.S. disability rights movement became cohesive via protests about the lack of enforcement of the Rehabilitation Act (Barnartt, 2008). From this, a few major American newspapers ran articles framing people with disabilities as a "new" minority group pressing for rights (Barnartt, 2008). Even advertising began embracing disability imagery in the 1980s. Longmore says TV ads with people with disabilities illustrated that advertisers no longer feared that "nondisabled consumers will be distressed or offended" (1987, p. 77). All these factors converged, we surmise, to give the U.S. entertainment industry the idea from the 1980s forward that featuring disability topics and disabled actors in their content would be OK.

However, some increased acknowledgement of disability issues in the news and a few added disabled characters on TV never gained true momentum. U.S. journalists have ignored or distorted many of the important civil rights issues facing people with disabilities for decades (Johnson, 2003; Haller, 2010). As for U.S. entertainment programming, as recently as September 2010, the inclusion group for disabled performers, I AM PWD, found that "scripted characters with disabilities represent only one percent of all scripted series regular characters — six characters out of 587 — on the five broadcast networks." Out of those six characters, only one is a disabled performer. I AM PWD says these data reflect the lack of employment opportunities for disabled performers, and it confirms the findings of our survey, in which people with disabilities say they want disabled performers to play disabled characters in TV and film. Therefore, the lobbying of journalists and the U.S. entertainment industry clearly needs to shift into high gear. Hopefully, this survey data will provide crucial data for those efforts.

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Table 1  
Rating of recent entertainment programs as stigmatizing or empowering

Program	Means on stigmatizing (1) to empowering scale (7) (n=390)
<i>Little people, Big world</i> (2006-2010)	5.32
<i>Finding Nemo</i> (2002)	4.97
<i>House</i> (2004-present)	4.60
<i>Monk</i> (2002-2009)	4.59
<i>Extreme home makeover</i> (2003-present)	4.2

Table 2  
Rating of programs as stigmatizing or empowering

Program	Means on stigmatizing (1) to empowering scale (7) (n=390)
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<i>Sesame Street</i> (1969-present)	5.66
<i>Children of a lesser god</i> (1986)	5.48
<i>A beautiful mind</i> (2001)	5.33
<i>Rain man</i> (1988)	4.54
<i>Dumb and Dumber</i> (1994)	2

Table 3  
Evaluation of models of representation in media

<u>Model</u>	<u>Means on rarely represented (1) to often represented (7) (n=390)</u>
Supercrip model perspective	5.34
Medical model perspective	5.33
Social Pathology model perspective	5.29
Business model	5.10
Legal model perspective	3.35
Minority/Civil Rights model perspective	3.02
Cultural Pluralism Model perspective	2.27

## The Effects of Disability on Earnings in China and the United States

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**Abstract:** This paper compares earnings disparities between persons with disabilities and able-bodied persons in the United States and in China, two countries with widely differing public policies regarding employment of persons with disabilities. In doing so, the paper provides readers with a unique comparative perspective on both the nature of disability policies in China and the United States and on the impacts of these policies. Data from the China Household Income Project Survey (CHIPs) and the US Current Population Survey (CPS) are used to estimate earnings equations in China and the US to test the hypothesis that the adverse impacts of disability on earnings differ between the two countries. The disability rates in the two samples are comparable as are the percentage differences in earnings between persons with disabilities and able-bodied persons. However, the estimated impacts of disability on wage and salary incomes are larger in the United States, where disability policy is essentially an anti-discrimination policy than they are in China, where disability policy includes an affirmative action requirement mandating that employers hire a quota of employees with disabilities against a threat of fines and penalties. The analysis has broad implications for understanding how and why anti-discrimination policies may not be enough to narrow earnings gaps between persons with disabilities and the able-bodied.

**Key Words:** disability policies, wage inequality, employment and disability

### Introduction and Motivation for the Analysis

This paper compares the effects of disability on wage and salary incomes in China and the United States. The motivation for the comparative analysis stems from the widely differing application of laws regarding disability in the two countries. In the United States, the Americans with Disability Act (ADA) is in essence an anti-discrimination law. Employers must not discriminate against persons with disabilities in hiring, promotions, training, pay, and other aspects of functioning in the workplace (<http://www.ada.gov/pubs/adastatute08.htm>).

By way of contrast, the 1991 Law on the Protection of Disabled Persons in China, which also prohibits discrimination against persons with disabilities, specifically contains a unique affirmative action mandate: all firms are required to hire a quota of persons with disabilities<sup>2</sup> (International Labor Organization, 2008). Would one expect the effects of disability on earnings in a country with an anti-discrimination mandate to be higher or lower than the effects in a country with an affirmative action and anti-discrimination mandate? In short, is anti-discrimination enough to overcome the adverse impacts of disability on earnings in labor markets?

Another motivation for the comparative analysis is that both countries produce conflicting measures of disability between different data sets. For example, in the United States,

one widely used data source on health and disability is the National Health Interview Survey (NHIS). Compilations from that data set reveal that in urban areas rates of persons with disabilities are lower than in rural areas. For the year 2000, for example, the urban rate for persons with disabilities, for people 18 to 60 years of age is calculated to be 8.15 percent whereas in rural areas it is found to be 12.27 percent<sup>3</sup> (U.S. Dept. of Health and Human Services, 2000). For the same year, the U.S. Census Bureau reported that 9.7 percent of persons ages 16 to 64 had sensory, physical, mental, or self-care disabilities (Erickson and Lee, 2005). However, in the Current Population Survey (CPS) data, compiled by the U.S. Census Bureau and the premier source of nationally representative information on wage and salary income and employment, the rates are 2.92 percent and 3.20 percent, respectively. In the NHIS data set, disability is defined as any health limitation; whereas in the CPS data set, disability refers to any lasting physical or mental health condition that causes difficulty working, limits the amount or type of work one can do, or prevents a person from working altogether. The CPS definition excludes temporary health conditions, such as broken bones or pregnancies. Time series information collected by Houtenville and Adler (2001) reveals self-reported rates of disability of between 7 percent and 10 percent for the period 1980 to 2000 in the United States. The Houtenville and Adler measures focus on work limitations due to both poor health and disability and thus may overstate the measure included in the CPS data, which distinguishes between poor health and the presence of a disability. In short, some United States government data sets, such as the CPS – which focus on non-institutionalized working age populations – produce disability rates considerably lower than other official data sets.

In China, there are also substantial differences in disability rates across different data sets. The main source of information on disability in China is the National Sampling Survey for Disability in China (Statistics Bureau of China, 2006) where the rural and urban disability rates for 2006 are found to be 6.95 and 5.29 percent, respectively. The most detailed source of information on income in China is the Chinese Household Income Survey (CHIPs). This data set is a sample drawn by researchers from the Chinese Academy of Social Sciences from data collected by National Bureau of Statistics. Analysis of that data set found an overall disability rate of 3.2 percent among the working age population, 18 to 60 years of age, with a rate of 6.2 percent in the urban sample and 1.4 percent in the rural sample (Myers & Ding, 2009). There are perceptible differences in the definitions of disability between the two Chinese surveys as well as between the rural and urban portions of the CHIPs survey, although the calculations for the urban areas in both data sets are remarkably similar.<sup>5</sup>

Thus, when using two data sets from two countries that focus on wage and salary incomes and that both report comparable measures of disability in China and the United States, does one find different disparities in income between persons with disabilities and able-bodied persons? The attractiveness of using the CHIPs and the CPS urban data sets is that both produce comparable percentages of persons with disabilities among those who work.

This paper proceeds in the following way. First, we sketch out some key features of disability and employment in China and the United States. Then, we describe the economic model of earning differentials between persons with disabilities and able-bodied persons, based largely on economic models of disability in the United States. We summarize the data and



present our results. In a concluding section, we discuss the alternative interpretations and policy implications of our findings.

## The Chinese Context

### Definition of Disability

In China, disability is officially defined as abnormalities or impairments of one or more of the following six abilities: visual, hearing, verbal, physical, intellectual, and psychiatric, according to the Second National Sampling Survey for Disability in China (NSSD). Notably excluded from the definition of disability in China are learning disabilities and disabilities caused by substance abuse (Hampton, 2001). The primary source of information on disability is The National Sampling Survey for Disability in China conducted in 1987 and 2006. The first survey targeted 29 provinces and involved 1.5‰ of the total population by group sampling (Statistics Bureau of China, 1987); these numbers increased to 31 provinces and 1.93‰ of the total population in the second survey (Statistics Bureau of China, 2006). There is limited information on economic characteristics and income in the NSSD, rendering this data set less useful for an analysis of labor market discrimination against persons with disabilities.

A second important source of information on persons with disabilities exists in the Chinese Household Income Project Survey (CHIPs). The urban sample consists of a stratified random of cities and towns (NBS, 2009b), where stratification is based on province and city and town size. The sampling of households within cities and towns results in a random population sample. For the purposes of the creation of the CHIP sample, households were selected randomly from provinces organized along the geographic distribution of the national population. Accordingly, the CHIP urban sample is regarded as a self-weighted sample. The 2002 urban sample covers 12 provinces with sampling units from 77 different cities. There are 20,632 persons in sampled urban households. In this survey, respondents are asked whether they have no symptoms, minor symptoms not requiring help, or major symptoms requiring help of eight different types of ailments. The eight range from visual impairments to mental illness.

### Demographics and Disability in China

According to the two national surveys, NSSD and CHIPs, the number of persons with disabilities increased from 51.6 million (4.9 percent of the total population) in 1987 (Statistics Bureau of China, 1987), to 83.0 million (6.34 percent of the total population) in 2006. Among persons with disabilities who were identified in 2006, 4.66 percent were under 14 years of age, 42.1 percent were between 15 and 59, 7.98 were between 60 and 64, and 45.26 were over 65 years old. In other words, the largest group of those with disabilities was the post-retirement group. Also according to the latest NSSD, 51.55 percent were male and 48.45 percent female; 24.96 percent lived in urban areas and 75.04 percent in rural areas. In 2006, the disability rates in urban and rural areas were about 3.6 percent and 8.4 percent, respectively, the latter being more than twice the former. In addition, seven provinces had a disability rate over 7 percent in 2006. They were: Jilin, Hebei, Henan, Sichuan, Guangxi, Xizang, and Gansu, more than half of them having considerable populations of Chinese ethnic minorities (Statistics Bureau of China, 2006).

## Employment and Income

The Chinese government's employment policies for persons with disabilities have been adjusted from time to time during the past decades. Such adjustments have shifted the policy approach from concentration to dispersion and are related to China's transition from a planned economy to a market economy, as argued by McCabe and Wu (2009) and Huang, Guo, and Bricout (2009). Yet the effectiveness of the policies at an implementation level is debatable. Fisher and Li (2008) point out that there was a "gap between the rhetoric of Chinese law and the experience of disability policy" and a "disjuncture between Chinese disability rights policy and independent living policy implementation." Also, the lack of training for people with disabilities and employers' negative attitudes toward hiring persons with disabilities posed two problems, Hampton (2001) alleges He contends that many companies would rather pay the fines for deliberately not hiring people with disabilities than follow the policies.

Hampton (2001) also argues that the most common job positions taken by people with disabilities are in "welfare enterprises" and in their own communities. As China transitioned to a market economy, most of these enterprises "faced cut backs or even shut downs" (Hampton, 2001). In such cases, employees with disabilities are unavoidably among the unfortunate ones who lose their jobs. In addition, Zhang and Hu (2008) describe how persons with disabilities experienced the most difficulty in the labor market and could only get lower positions and salaries. They conclude that the development of employment for people with disabilities was unbalanced among different regions and different kinds of jobs that could be done by people with different types of disability. Moreover, the attitude of persons with disabilities toward taking a job seems ambivalent. McCabe and Wu (2009) suggest that among persons with disabilities taking a job was regarded as "mutually beneficial." Yet Pierini, Pearson, and Wong (2001) describe a dilemma faced by persons with disabilities of wanting to make contact with society and fearing the assumption of responsibilities.

As for the economic status, the 2006 Survey reports that the average total income of a person with a disability in 2005 was RMB 4864 in urban areas and RMB 2260 in rural areas, both less than half of their able-bodied counterparts (Statistics Bureau of China, 2006). Liu, Zhang, and Zhang (2007) conducted an investigation of the socioeconomic status of persons with disability and found that 66.4 percent of those investigated had a monthly income below the minimum subsistence level.

In short, the literature on disability and economic status in China clearly points to a disadvantaged position for persons with disabilities. However, this is against a backdrop of policy initiatives that putatively provides affirmative benefits to persons with disabilities.

## The US Context

### Definition of Disability

The 2000 U.S. Census defines disability as (a) blindness, deafness, or a severe vision or hearing impairment; (b) a substantial limitation in the ability to perform basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying; (c) difficulty learning,

remembering, or concentrating; or (d) difficulty dressing, bathing, or getting around inside the home (Erickson & Lee, 2005). Building on the Census definition of disability, the American Community Survey (ACS) – a recent effort to collect information at the community level during inter-Census years -- codes an individual as being disabled if the person or a proxy respondent claims: a) to be deaf or to have serious difficulty hearing; b) to be blind or to have serious difficulty seeing even when wearing glasses; c) to have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition; d) to have serious difficulty walking or climbing stairs; e) to have difficulty dressing or bathing; or f) to have difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition. These six conditions – referencing respondents in most instances who are five years or older -- are recoded as Hearing Disability, Visual Disability, Cognitive Disability, Ambulatory Disability, Self-care Disability, and Independent Living Disability (Erickson, et al., 2010).

The Census definition is in stark contrast to the designation available when using in the Current Population Survey, which has been conducted continuously since 1948. Sponsored jointly by the U.S. Census Bureau and the U.S. Bureau of Labor Statistics (BLS), the Current Population Survey (CPS) is the primary source of labor force statistics for the population of the United States (see <http://www.census.gov/cps/>).<sup>6</sup> The CPS identifies persons who had "a health problem or a disability which prevents him/her from working or which limits the kind or amount of work." This question is followed by a follow-up question concerning the receipt of income as the result of a health problem. Respondents were not supposed to refer to short, acute illnesses (e.g., influenza) or temporary conditions (e.g., pregnancy or broken bones). One can construct from these responses an indicator of "good health" as meaning a person who is not restricted in their employment by poor health.

Still another conceptualization of disability comes from the National Institutes of Health (NIH), which defines disability as the following:

"Disability is a general term that refers to any long- or short-term reduction of a person's activity as a result of an acute or chronic condition. *Limitation of activity* refers to a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group. *Restriction of activity* refers to particular kinds of behavior usually associated with a reduction in activity due to either long or short-term conditions. Thus limitation of activity refers to what a person is generally capable of doing, but restriction of activity ordinarily refers to a relatively short-term reduction in a person's activities below his or her normal capacity." (National Center for Health Statistics, 1988, p. 140)

Accordingly, the NIH definition of disability is broader and only imperfectly related to work behavior. The Census and the ACS definitions are more specific in detailing the specific type of limitation of one's life's activities. The CPS definition is narrower and focuses on conditions that limit employment.

## Demographics of Disability

Data from the 2000 U.S. Census, the American Community Survey as well as from the Current Population Survey, all show a common demographic profile of persons with disabilities: higher disability rates for American Indians and African Americans than for white non-Hispanics, Asians or Hispanics; and higher disability rates for persons in the post-retirement ages than for persons in the working ages. For example from the 2009 American Community Survey, and among persons 21 to 64 in the non-institutionalized population, 10.4 percent of white non-Hispanics were disabled; 14.1 percent of blacks were disabled; 8.3 percent of Hispanics were disabled; 4.4 percent of Asians were disabled; and a phenomenal 19.0 percent of American Indians were disabled (Erickson, Lee & von Schrader, 2011).<sup>7</sup>

## Employment and Income

Persons with disabilities in the United States are far less likely to be employed than are able-bodied persons. And, among those who are employed, persons with disabilities earn less than those who are able-bodied. According to estimates from the American Community Survey, in 2009 non-institutionalized persons with disabilities aged 21-64 years working full-time/full-year earned median annual earnings of \$35,000. The median annual earnings of non-institutionalized persons aged 21-64 years without a disability in the United States who were working full-time/full-year in 2009 was \$41,000. But, the vast majority of persons with disabilities in this same age group did not work. The employment rates for white males are estimated to be 41.0 percent; for white females, 33.6; for blacks, 28.7 percent; for Hispanics, 38 percent; and for Asians, 39.3 percent. Moreover, the employment rates for persons with disabilities vary by education completion. Among persons with disabilities, the employment rate was 22.8 percent for those with no high school degree; it was 33.6 percent with only a high school degree; it was 41.5 percent for those with some college; and it was 54.8 percent for college graduates. In short, earnings for full time employed/year workers are lower for persons with disabilities than for able-bodied persons, a disproportionate share of persons with disabilities are not employed, and the employment rates among persons with disabilities are highest among white males, Asians and Hispanics and are lowest among those with the least education.

Consistent with the data from the American Community Survey, the Center for an Accessible Society reports that 30 percent of working aged persons with disabilities in the United States are unemployed. They contend that a central explanation is employer discrimination:

“Part of the problem is discrimination, and part recent court rulings favoring employers in ADA lawsuits. Discrimination against people with disabilities is, unfortunately, alive and well, despite the legal prohibitions against discrimination in hiring people with disabilities. Seventy-nine percent of disabled people who are unemployed cite discrimination in the workplace and lack of transportation as major factors that prevent them from working. Studies have also shown that people with disabilities who find jobs earn less than their co-workers, and are less likely to be promoted.

Unfavorable court rulings have not been helpful, either. Research by law professor Ruth Colker of Ohio State University has shown that in the eight years after the ADA went into effect, employer-defendants prevailed in more than 93 percent of the cases decided

by trial. Of the cases appealed, employers prevailed 84 percent of the time” (Center for an Accessible Society, 2009).

One cannot conclude, however, from descriptive evidence alone the underlying causes of disparities in earnings between persons with disabilities and able-bodied persons. In the next section, we present a model of earnings disparities that permits one to isolate the independent impacts of disability on earnings.

### Modeling of the Effects of Disability on Earnings

Conventional economic wisdom suggests that market wages are determined by productivity. Individual human capital variables including experience, education, and training (captured conventionally by measures of age and education) are at the forefront in the determination of wages. Institutional factors (e.g. unionization) and contextual factors (such as location or local market conditions) also matter. Why might there be *group* differences in market wages? Disparities in market wages by group membership might arise because employers have tastes for discrimination (Becker, 1957) or because employers are unable to observe individual productivity-related factors (such as skills) and these unobserved factors are believed to be unequally distributed among groups (Arrow, 1998). In both instances testable hypotheses are derived wherein one can distinguish between observed factors that differentiate between groups that explain earnings gaps and unobserved factors (Darity, 1995).

What is particularly germane about disability is that although members of the group might be thought to be less productive or are believed to have different productivity characteristics than those who are not disabled, there is a wide variance in both observed and unobserved characteristics of these populations. For example, persons who are blind might excel in music or computer science. They are visibly different from able-bodied persons, even though their work performance may be largely unaffected by their disability. Persons suffering from certain types of mental illness such as depression or schizophrenia may not appear to be different from able-bodied persons when hired – particularly early in their careers – and may well excel initially if treated. Untreated mental illness might result in adverse impacts on work behavior. This suggests that observed and unobserved disabilities may have different impacts on productivity.

Aside from discrimination in labor markets that might reduce the incomes of persons with disabilities, there is a countervailing influence of disability payments to persons who do not work. Haveman and Wolf (2001) point out that there are non-trivial work disincentives associated with disability programs that may increase non-labor income but at the expense of lowering labor income. The net impacts depend in part on the type, severity and duration of disability.

In the simplest of tests of the hypothesis that there are statistically significant differences in income,  $y$ , between persons with disabilities and able-bodied persons, one can estimate the following regression equation:

Equation 1:

$$\ln y_i = \alpha + \phi D_i + \mu_i$$

Where for the  $i$ th individual  $\alpha$  is a constant term,  $\mu_i$  is an error term, and  $D_i$  is a dichotomous variable equal to 1 if the  $i$ th wage recipient is a person with a disability and equal to 0 otherwise. We estimate the natural logarithm of wage and salary earnings,  $\ln y_i$ , to account for the fact that earnings are always positive for persons who work. The test of the hypothesis that there is no difference in (natural log) earnings between persons with disabilities and able-bodied persons is the test of the hypothesis that  $\phi=0$ .

But, economic theory suggests that there are other determinants of wage and salary income. These include  $j$  independent variables: age, education, location, gender, race and ethnicity, type of employer, health status, and when available, measures of performance. Thus, one can re-estimate equation 1 to obtain:

Equation 2:

$$\ln y_i = \sum \beta_j X_{ij} + \phi' D_i + \varepsilon_i$$

where the  $x$ 's are independent factors explaining wage and salary incomes, the  $\beta$ 's are the effects of these factors on income,  $D_i$  is a dichotomous variable indicating whether the respondent is a person with disability or not, and  $\phi'$  is the percentage difference in income between respondents who are persons with disabilities and those who are able-bodied that is not explained by the  $x$ 's. The normal assumptions of the error term  $\varepsilon_i$  are made: identically and independently, normally distributed with zero mean and constant variance.

Generally speaking, one expects that  $\phi'$  is less than  $\phi$  in absolute value. In other words, without controlling for human capital or other factors, the effect of disability on earnings would be larger (in absolute value) than the effect estimated from a model that accounts for other relevant determinants of income.

Now, the model can be estimated for a subset of the population that is in good health. This model is particularly attractive because of the possible confounding influence of disability and health. In this version of the model, the estimated coefficient  $\phi^h$  – where the superscript  $h$  denotes good health -- should vanish if there is no discrimination against persons with disabilities and ought to be smaller in absolute value than  $\phi'$  if only because poor health could be a pretext for paying lower wages to persons with disabilities. Equation 2 only controls for the independent impacts of health and not the various interactions between health status, disability, and other factors. Thus, estimating equation 3, which is restricted to persons in good health, is akin to accounting for the interactions between health, disability, and other factors. The superscript  $h$  denotes that the variables are all measured for persons in good health.

Equation 3:

$$\ln y_i^h = \sum \beta^h_j X^h_{ij} + \phi^h D_i^h + \varepsilon_i$$

It is also possible to compare the coefficients across two different policy conditions: one country with an anti-discrimination mandate only (the case of the United States) and another country with an affirmative action mandate in addition to an anti-discrimination mandate (as is the case of China). Accordingly, we estimate equations 1, 2, and 3 for all workers separately in urban China and the United States.

Halvorsen and Palmquist (1980) and Thornton and Innes (1989) show that technically speaking  $\phi$  should not be interpreted as the percentage difference in wage and salary incomes between workers with disability and able-bodied workers. Rather, the “exact” measure is given by  $\exp(\phi)-1$ , an adjustment necessitated by the fact that the underlying equation is a semi-logarithmic equation and not a linear equation. This adjustment is made in the analysis that follows our description of the data.

## The Data

### The Chinese Sample

The China Household Income Project (CHIP) was assisted by the General Team of Rural and Urban Surveys at the National Bureau of Statistics (NBS) that conducted fieldwork in early 2003. The sample was drawn from a larger sample used by the (NBS) in its annual household survey covering 67,000 rural and urban households, through a multi-stage random sampling. Our analysis is restricted to the urban sample, where wage and salary income information is more readily available than in the rural sample. There are 20,632 persons in sampled urban households. Of those persons, 11,217 are between the ages of 18 and 60 with positive wage or salary incomes. The average wage and salary income for this subgroup in 2002 was RMB 8,036. For persons with disabilities, the average was RMB 5,379. For those without disabilities, the average was RMB 8,125. Thus, in urban China, there was a -33.80 percent difference between earnings of persons with disabilities and those without disabilities. In the urban sample of 18 to 60 year olds, 3.2 percent reported disabilities, as computed from the CHIPS 2002 data (Shi, 2009)

### The United States Sample

The Current Population Survey (CPS) is a monthly survey of labor force characteristics. It samples the civilian non-institutional population 16 years and older and contains a rotating sample of 60,000 households. The annual demographic survey (March Supplement) contains detailed information on education, family status, disability, and health and related measures along with annual wage and salary income. For comparability with the Chinese data, we have restricted the data set to persons 18 to 60 with positive wage and salary incomes. A total of 71,964 persons met these criteria in 2002. The average wage and salary income was \$39,271. For persons with disabilities, the average was \$24,582. For those without disabilities, the average was \$39,587. Thus, in the urban United States, there was a -37.90 percentage difference between the earnings of persons with disabilities and those without disabilities, as computed from the CPS data. (King, et al. 2010).

## Descriptive Statistics

Table 1 provides descriptive statistics on the two samples. In the China urban sample, restricted to working age persons 18-60, the share of persons who report disabilities is 3.2 percent. In the United States, the disability share is lower at 2.1 percent. The average age in the China sample is 40; in the US sample, it is 38. Persons with disabilities in both samples are older than able-bodied persons and the percentage difference in ages between persons with disabilities and able-bodied persons are about the same at 10 percent. In the China sample, 4.2 percent of persons are minority group members with slightly higher minority shares among persons with disabilities as compared to the able-bodied. In the US sample, 32.5 percent are non-white or Hispanic. But the distribution by race/ethnicity differs greatly among groups. For example, there is a larger share of Asians and Hispanics among the able-bodied than among persons with disabilities. There is a larger share of blacks and American Indians among those with disabilities than the able-bodied. Gender distributions differ between the China and US samples also. In the China sample, there are no gender differences in the percentages of persons with disabilities and the able-bodied. In the US sample, 51.3 percent of persons with disabilities are female, while 46.7 percent of able-bodied persons are female. In both the China and US samples, persons with disabilities are less educated than are able-bodied persons; are more likely to be in poor health, and to be household heads. Contrary to evidence from other literature, Table 1 shows a lower share of employment in the public sector for persons with disabilities than able-bodied persons in China; in the US there is no difference in public sector employment shares between the two populations.

### Health Status

Both the CHIPS data and the CPS data make sharp distinctions between poor health and disability. In the CHIPS data, persons are asked – apart from the disability questions – to compare their health to persons of the same age. Possible responses are: very healthy, healthy, just so-so, bad or very bad. We have coded “bad health” to reflect responses “bad” or “very bad.” All other values are coded as “good health.” In the CPS sample, persons are asked to indicate whether they have any health limitations that affect their ability to work. Those who respond affirmatively are deemed to have “bad health.” Others are defined as in “good health.” Clearly, from Table 1, we see that not all persons who are disabled are in bad health, even though the incidence of self-reported bad health is higher about persons who are disabled than among able-bodied persons. About five percent of persons in both samples report being in bad health. Among persons who are disabled, 42.2 and 38.5 percent report being in bad health in China and the USA respectively. Among able-bodied persons, the rates are 3.7 percent and 4.7 percent. In short, although there are clear differences in the rates of self-reported bad health between persons with disabilities and able-bodied persons, the vast majority of persons with disabilities in both samples report being in good health. These rates, remarkably similar in China and the USA, confirm that the “bad health” variable is not tautologically the same as the disability variable in the data sets.

Table 1:



Descriptive Statistics in the China and US Samples								
	CHINA				UNITED STATES			
	Total	Persons with Disabilities	Able-Bodied Persons	Percentage difference	Total	Persons with Disabilities	Able-Bodied Persons	Percentage difference
Persons with Disabilities	0.032				0.021			
AGE	40	44	40	10.00%	38	42	38	10.30%
Non-Han	0.042	0.046	0.042	9.52%				
White-Non Hispanic					0.675	0.730	0.674	8.34%
Hispanic					0.143	0.091	0.144	-36.63%
Black/Negro Non Hispanic					0.122	0.131	0.122	7.02%
American Indian/Aleut/Eskimo Non Hispanic					0.006	0.020	0.006	216.77%
Asian or Pacific Islander Non Hispanic					0.053	0.028	0.054	-47.50%
FEMALE	0.510	0.509	0.510	-0.20%	0.468	0.513	0.467	9.89%
EDUCATION								
Less than High School	0.322	0.545	0.314	73.57%	0.107	0.129	0.107	20.52%
High School or Some College	0.583	0.409	0.588	-30.44%	0.580	0.671	0.578	16.11%
Bachelor's Degree	0.088	0.045	0.091	-50.55%	0.212	0.137	0.214	-35.95%
More than College	0.006	/	0.006		0.100	0.063	0.101	-37.71%
BAD HEALTH	0.050	0.422	0.037	1040.54%	0.054	0.385	0.047	712.92%
EMPLOYED IN PUBLIC SECTOR	0.445	0.269	0.451	-40.35%	0.150	0.149	0.150	-0.87%
HOUSEHOLD HEAD	0.396	0.411	0.395	4.05%	0.514	0.611	0.512	19.40%
2002 CHIPS URBAN SAMPLE, AGES 18-60					2002 CPS URBAN SAMPLE, AGES 18-60			

Table 2 reports the differences in wage and salary incomes across different characteristics of workers. The percentage gap in earnings between persons with disabilities and able-bodied persons is lower in the China sample than it is in the US sample. Earnings are lower for persons with disabilities than for the able-bodied across all age groups, for both male and female, for household heads and non-heads, and for those in good health and in bad health in the China sample as well as in the US sample. Notably different, however, are the earnings gaps by education level in the China sample vs. the US sample. In the US sample, earnings are lower in each educational category for persons with disabilities than for able-bodied persons. However, in the China sample, college graduates with disabilities actually earn more than their able-bodied counterparts. This finding is consistent with an affirmative action policy that favors the better educated among persons with disabilities.

Table 2:

Average Wage and Salary Income, China and USA 2002								
	CHINA (Yuan)				UNITED STATES (Dollars)			
	Total	Persons with Disabilities	Able Bodied Persons	Percentage difference	Total	Persons with Disabilities	Able Bodied Persons	Percentage difference
<b>Total</b>	8,036	5,379	8,125	-33.80%	39,271	24,582	39,587	-37.90%
<b>Race/Ethnicity</b>								
HAN (White Non-Hispanic)	8,041	5,325	8,130	-34.50%	43,828	26,653	44,228	-39.74%
Non-Han (Hispanic)	7,930	5,671	8,014	-29.23%	25,583	18,226	25,684	-29.04%
Black/Negro Non Hispanic					29,321	19,357	29,551	-34.49%
American Indian/Aleut/Eskimo Non Hispanic					31,041	17,204	31,983	-46.21%
Asian or Pacific Islander Non Hispanic					42,155	20,963	42,395	-50.55%
<b>Gender</b>								
Male	9,814	6,035	9,941	-39.29%	47,448	26,381	47,862	-44.88%
Female	6,330	4,748	6,383	-25.61%	29,976	22,876	30,144	-24.11%
<b>Education</b>								
Less than High School	4,995	2,813	5,120	-45.06%	18,786	12,731	18,943	-32.79%
High School or Some College	8,935	7,584	8,967	-15.42%	30,921	21,821	31,148	-29.94%
Bachelor's Degree	12,790	15,724	12,740	23.42%	54,322	38,542	54,539	-29.33%
More than College	17,856	/	17,882		77,651	47,915	78,049	-38.61%
<b>Age</b>								
less than 30	4,125	3,280	4,142	-20.81%	22,473	14,950	22,568	-33.75%
[30,45)	9,734	7,272	9,800	-25.80%	42,828	25,006	43,189	-42.10%
Greater than 45	8,023	4,599	8,189	-43.84%	48,677	27,577	49,325	-44.09%
<b>Health</b>								
Good Health	8,148	6,795	8,175	-16.88%	39,870	27,300	40,044	-31.83%
Bad health	6,019	3,438	6,926	-50.36%	28,878	20,242	30,387	-33.39%
	2002 CHIPS, Urban Sample, Ages 18-60				CPS, Urban Sample, Ages 18-60			

## Regression Results

Table 3 reports the results of estimating equations 1 and 2 for all workers and equation 3 for healthy workers (i.e. those who are in good health). The table shows the results separately for China and the United States. The first row in the table reports the estimated coefficients on  $\phi$ ,  $\phi^d$ , and  $\phi^h$ , the effects of disability status on log-earnings. All estimates are negative and statistically significant at the 1 percent level. In both the China and US samples, earnings increase with age and education, are higher for household heads, and lower for females and persons in poor health. In the US sample, racial and ethnic minorities earn less than non-minorities; in the China sample there are no statistically significant differences in earnings between urban minorities and Han, the majority group.

Table 3:

ESTIMATED COEFFICIENTS IN LOG-LINEAR MODEL OF WAGE AND SALARY INCOME, 2002						
	CHINA URBAN SAMPLE			USA Urban Sample		
	(1)	(2)	(3)	(1)	(2)	(3)
Disabled	-0.3811 (0.000)**	-0.1829 (0.005)**	-0.2147 (0.007)**	-0.799 (0.000)**	-0.5616 (0.000)**	-0.5189 (0.000)**
Age		0.0987 (0.000)**	0.0998 (0.000)**		0.1472 (0.000)**	0.1506 (0.000)**
Age squared		-0.0012 (0.000)**	-0.0012 (0.000)**		-0.0016 (0.000)**	-0.0016 (0.000)**
High School or Some College		0.3732 (0.000)**	0.3682 (0.000)**		0.4178 (0.000)**	0.4144 (0.000)**
Bachelor's Degree		0.6952 (0.000)**	0.6837 (0.000)**		0.8429 (0.000)**	0.8412 (0.000)**
More than College		0.8621 (0.000)**	0.853 (0.000)**		1.0978 (0.000)**	1.0928 (0.000)**
Household Head		0.168 (0.000)**	0.1711 (0.000)**		0.1465 (0.000)**	0.1454 (0.000)**
Public Sector Employment		0.6048 (0.000)**	0.5973 (0.000)**		-0.0396 (0.000)**	-0.046 (0.000)**
Bad Health		-0.0913 (0.036)*	/		-0.2413 (0.000)**	/
Female		-0.2333 (0.000)**	-0.239 (0.000)**		-0.4191 (0.000)**	-0.4194 (0.000)**
Minority(Non-Han)		0.0068 (0.866)	-0.0043 (0.916)			
Hispanic					-0.1304 (0.000)**	-0.1339 (0.000)**
Black/Negro Non Hispanic					-0.1714 (0.000)**	-0.1683 (0.000)**
American Indian/Aleut/Eskimo Non Hispanic					-0.1285 (0.003)**	-0.135 (0.002)**
Asian or Pacific Islander Non Hispanic					-0.1325 (0.000)**	-0.1371 (0.000)**
Constant	8.9596 (0.000)**	6.7255 (0.000)**	6.7132 (0.000)**	10.086 (0.000)**	6.7503 (0.000)**	6.7029 (0.000)**
Observations	11217	11186	10692	71964	67470	63867
R-square	0.004	0.314	0.3146	0.014	0.3262	0.3288

**Robust p values in parentheses; province/state dummies included in equations (2) and (3)**

\* significant at 5%; \*\* significant at 1%

Finally, whereas in the US sample earnings are lower for workers in the public sector, in the China sample, public sector workers and those in state-owned enterprises earn more than workers elsewhere.

Table 4 gathers the results of estimating  $\phi$  for the various models and displays both  $\phi$ , the estimated coefficient on disability, and  $\exp(\phi)-1$ , the exact measure of the percentage difference in earnings due to disability.

Table 4

Comparison of Percentage Differences in Wage and Salary Incomes Due to Disability, United States vs China						
	United States		China		United States/China	
	$\phi$	$\exp(\phi)-1$	$\phi$	$\exp(\phi)-1$	$\phi$	$\exp(\phi)-1$
(1) Unadjusted	-79.90%	-55.02%	-38.11%	-31.69%	2.10	1.74
(2) Adjusted	-56.16%	-42.97%	-18.29%	-16.71%	3.07	2.57
(3) Adjusted, Healthy Sample	-51.89%	-40.48%	-21.47%	-19.32%	2.42	2.10

Note: The unadjusted estimates of  $\phi$  are obtained from a log-linear regression of wage and salary income on disability status. The estimate  $\exp(\phi)-1$  is the "exact" measure of the percentage difference in earnings due to disability status; the adjusted estimates of  $\phi$  and  $\exp(\phi)-1$  include in the regressions, age, age-square, education, gender, race/ethnicity, health status, type of employment, and province/state dummies. All estimates are statistically significant at the 5 percent level.

### Implications

There are negative and statistically significant impacts of disability on wage and salary earnings in all models and in both the US and China samples. However, the magnitude of these adverse impacts of disability on earnings is consistently larger in the United States than in China. Without controls for any factors at all, the adverse impacts of disability status on earnings are larger than they are when one controls for human capital and other relevant factors. For example, the estimated percentage difference in earnings between workers with disability and able-bodied workers in the United States without controls is -55.02 percent. Once one controls for relevant factors, the percentage difference drops (in absolute value) to -42.97 percent. In the China data set, the unadjusted difference is -31.69 percent. When one controls for human capital and other relevant factors the difference drops to -16.75 percent. The last column of table 4 reports the ratios of the United States to China estimates of the effects of disability on earnings. The ratio ranges from 1.74 to 3. The adverse impacts of disability on earnings are more than twice as large in the United States as in China controlling for relevant determinants of earnings.

In the healthy sample, the negative impacts of disability are more than twice as large in the United States as they are in China. The estimated effects are smaller (in absolute value) for healthy persons than for all workers in the United States. The exact measure of the percentage difference in earnings due to disability, controlling for relevant factors, is -40.48 percent in the healthy sample as compared to -42.97 among all workers in the United States, a small but non-trivial difference. In China, however, the percentage gap in earnings due to disability is larger in the healthy sample as compared to the overall sample, with exact measures equal to -19.28 percent vs. -16.75 percent. The result is that the ratio of the disability effect on earnings in the

United States to the disability effect on earnings in China is lower among healthy workers than it is among all workers. Yet, even among healthy workers, the ratio exceeds two. In short, the negative impacts of disability on earnings are larger in the United States than they are in China even among healthy workers.

## Summary and Conclusions

China is unique among emerging international economic powers in the sense that it provides explicit affirmative action for persons with disabilities. The requirement in China that both state-owned enterprises and private companies employ a certain proportion of workers with disabilities is in stark contrast to the United States where federal policy mandates that employers not discriminate against persons with disabilities in hiring, promotions, wages, or other aspects of the work experience. Indeed, ADA's requirement that employees not be required to reveal their disability during a job interview or employment application process can be viewed strictly as an anti-discrimination mechanism as opposed to the affirmative action *requirement* in China that firms hire workers with disabilities.

Our results show that there are measureable differences in the adverse impacts of disability between the urban, working age samples in the United States and in China. The immediate interpretation of these results is that reductions in earnings due to disability depend critically upon the institutional and legal context in which disability policy is set. Since we have controlled for exactly the same factors in the models estimated for both the US and China, and since the samples are comparable with respect to age and urban location, the differing sizes of the coefficients on the disability effect can be interpreted as attributable to differences in policies between China and the US. The models control for differences in province or state, but they do not control for nuanced differences in the definitions of disability.

Kohrman (2003) notes that the official statistics on disability in China are suspect, because they are collected in a highly political environment where the goal is to produce a disability rate that is neither too high – a possible challenge to the central government -- nor too low, wherein the data will not be believable to international observers. The CHIPS data seem to overcome many of the objections of Kohrman. The data set is not designed to measure disability and, like the Current Population Survey, the disability rates are realistically low among persons who are employed. The resulting disability rates in urban China are remarkably similar to the disability rates among working age persons in the United States. The relatively low levels of disability rates observed in the CPS data of persons who have wage and salary incomes is consistent with the work disincentive effects of disability insurance reported widely (Acemoglu & Angrist, 2001; Haveman & Wolf, 2000) in the economics literature.<sup>8</sup>

We have resisted using the term “discrimination” to describe our estimated impacts of disability on earnings. In a formal test of discrimination against persons with disabilities prior to ADA, DeLeire (2001) estimated that only a small portion of the earnings gap between persons with disabilities and able-bodied persons can be attributed to discrimination, in the sense that identically situation persons are treated unequally. He contends that earnings gaps widened after ADA's passage and that employment of persons with disabilities declined. The estimation procedure employed in this paper does not permit us to distinguish between gaps in earnings due

to unequal treatment of identically situated individuals and differences in productivity between persons with disabilities and able-bodied persons. However, the fact that we still obtain a sizeable disparity in earnings even among persons who report good health in 2002 suggests that disability status exerts a non-trivial impact on wage and salary earnings.

Absent empirical evidence to the contrary, the central conclusion from this paper is that the adverse impacts of disability on earnings of working age adults in urban areas are smaller in China than in the USA. This perhaps surprising conclusion comes about despite the widespread perception that persons with disabilities in China have fewer opportunities and are more restricted in their access to schools, workplaces, and public accommodations than persons with disabilities in the United States. Visitors to the 2008 Beijing Olympics routinely complained about lack of access and physical barriers preventing many persons with disabilities from navigating successfully around the city. Another example is the case of hearing impaired and deaf children who are unable to complete school beyond the primary grades due to a lack of access to facilities that would help them integrate into mainstream classrooms. Because the Chinese language relies heavily on tones, lip reading is nearly impossible. And Chinese sign language is not widely understood outside of large urban areas. In the United States, by way of contrast, most public buildings must meet stringent accessibility standards and American Sign Language is widely understood in diverse quarters. Most major television shows are captioned for the deaf and hearing impaired and there is an extensive system for relaying telephone calls between hearing and deaf or hearing impaired customers, services conspicuously absent even in major Chinese cities. Thus, all things considered, one would expect larger negative impacts of disability on earnings in China than in the United States. That this is not the case, we contend, is due to labor market policy differences between the two countries. In one area that matters, wage differentials, China's affirmative action policies produce better results for persons with disabilities than the anti-discrimination policies of the USA.

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Endnotes

<sup>1</sup> “Title I requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. For example, it prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. It restricts questions that can be asked about an applicant’s disability before a job offer is made, and it requires that employers make reasonable accommodation to the known physical or mental limitations of otherwise qualified individuals with disabilities, unless it results in undue hardship.” A Guide to Disability Rights Laws, U.S. Department of Justice, Civil Rights Division Disability Rights Section, September 2005. [www.ada.gov/cguide.htm](http://www.ada.gov/cguide.htm), (downloaded, August 5, 2010).

<sup>2</sup> “The Government has established a quota system that requires all public and private employers to reserve no less than 1.5% of job opportunities for persons with disabilities, in accordance with specific regulations established by local provincial governments.” International Labor Organization, Facts on People with Disabilities in China [www.ilo.org/public/english/region/asro/beijing/.../disabilities.pdf](http://www.ilo.org/public/english/region/asro/beijing/.../disabilities.pdf) (downloaded, August 5, 2010)

“The right to work is guaranteed by the law in China, which states that, ‘No discrimination shall be practiced against disabled persons in employment, engagement, status regularization, promotion, determining technical or professional titles, payroll for labor, welfare, labor insurance or in other aspects.’ Employers in China, such as state-run welfare enterprises, should apparently not deny people with disabilities employment.” Overview of Disability in China, March 16, 2010, [www.disabled-world.com/news/asia/china/disability-china.php](http://www.disabled-world.com/news/asia/china/disability-china.php), (downloaded, August 5, 2010)

“Law on Protection of Disability” (中华人民共和国残疾人保障法) was enacted in 1991. Article 30 in this law points out that “Government departments, institutions, organizations, enterprises and collectives in urban or rural should employ the disabled according to some certain proportion”. (第三十条指出：“机关、团体、企业事业组织、城乡集体经济组织，应当按一定比例安排残疾人就业，并为其选择适当的工种和岗位”。) In the original law, there is no specific proportion mentioned.

Thereafter, “Temporary Management Stipulation on the Disabled Employment Security Foundation” (《残疾人就业保障金管理暂行规定》) was enacted in 1995. Article 2 in this stipulation says that based on Law on Protection of Disability, Provinces, Autonomous Regions and municipalities should collect funds for those units did not employ a certain proportion disabled.

（“保障金”是指在实施分散按比例安排残疾人就业的地区，凡安排残疾人达不到省、自治区、直辖市人民政府规定比例的机关、团体、企业事业单位和城乡集体经济组织，根据地方有关法规的规定，按照年度差额人数和上年度本地区职工年平均工资计算交纳用于残疾人就业的专项资金。“保障金”按属地原则交纳，中央部门所属单位按照所在地地方法规的有关规定办理。） The proportion is not specifically stated in this law. The precise proportion appears to vary by province prior to 2007. For example, in Guangdong Province the proportion was 1.5 percent. But in Beijing it was 1.7 percent. However, the latest version of the law,

《广东省分散按比例安排残疾人就业办法》（广东省第九届人民代表大会常务委员会（第89号公告）），2000年7月28日广东省第九届人民代表大会常务委员会第十九次会议通过。

（“Ways on Employing the Disabled According to Proportion in Guangdong Province”, (The Ninth People’s Congress Standing Committee of Guangdong Province (the 89th Public Notice)) was authorized by The Ninth People’s Congress Standing Committee of Guangdong Province on July 28th 2000.

《北京市按比例安排残疾人就业办法》（北京市人民政府令（1994年第10号）），1994年5月13日经北京市人民政府常务会第32次会议通过。

“Ways on Employing the Disabled According to Proportion in Beijing”, (Mandate of People’s Government of Beijing (the 10th 1994)) was authorized by the 32nd Executive Council of People’s Government of Beijing on May 13th 1994.)

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<sup>3</sup> U.S. Dept. of Health and Human Services, National Center for Health Statistics. NATIONAL HEALTH INTERVIEW SURVEY, 2000 [Computer file]. 2nd ICPSR version. Hyattsville, MD: U.S. Dept. of Health and Human Services, National Center for Health Statistics [producer], 2000. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 2002. doi:10.3886/ICPSR03381. <http://www.icpsr.umich.edu/cgi-bin/SDA/ICPSR/hsda?nacda+03381-0003>

<sup>4</sup> Erickson and Lee, 2005.

<sup>5</sup> The question asked in the rural questionnaire is:

是否有残疾或智障?

Which translates roughly to: *Do you suffer from deformity or amentia?* An alternative translation is: *Do you suffer from disability or mental illness or disability?*

In the urban questionnaire, a similar question is posed:

您是否具有以下残疾或虚弱的身体特征?

This translates to: *Do you have the body characteristics of deformity or debility?* An alternative translation is: *Do you have the following disability or weakness of the physical characteristics?* Urban respondents are then asked eight specific disability-related questions with three possible answers: (1) not at all, (2) minor symptoms and without any assistance, and (3) serious symptoms or needs assistance. The eight additional disability questions are:

*Question 1: physical disability or Hemiplegia*

(身体残疾或偏瘫)

*Question 2: visually impaired*

(视力障碍)

*Question 3: hearing impaired*

(听说障碍)

*Question 4: mental illness*

(精神类疾病)

*Question 5: mental disability*

(智力障碍)

*Question 6: infirmity*

(体弱多病)

*Question 7: chronic ailment or complaint*

(慢性病)

*Question 8: other disability*

(其他残障)

A person is defined as being disabled if, in the urban questionnaire, the response to Questions 1, 4, 5, or 8 denotes minor or serious symptoms with or without the need for assistance; or the response to Questions 2, 3, 6, or 7 denotes serious symptoms and needs assistance; or if the response to the disability question in the rural questionnaire is “yes.”

<sup>6</sup> The CPS consists of approximately 60,000 occupied households. The CPS sample consists of independent samples in each of the 50 states and the District of Columbia. There are 2,025 (primary sampling units (PSUs)—most of which comprise a metropolitan area, a large county, or a group of smaller counties).

<sup>7</sup> These statistics were calculated by the Cornell University Employment and Disability Institute using the U.S. Census Bureau's 2009 American Community Survey (ACS) Public Use Microdata Sample (PUMS) data. Erickson, W., Lee, C., von Schrader, S. (2010). Disability Statistics from the 2009 American Community Survey (ACS). Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC). Retrieved Nov 23, 2011 from [www.disabilitystatistics.org](http://www.disabilitystatistics.org). The authors note the following: *Caution should be used when interpreting a statistic based on small base populations or when the confidence interval is large.* Readers should consult the original reference for the sample sizes and confidence intervals for the statistics reported.

<sup>8</sup> In addition to the work disincentive effect of disability insurance income, Acemoglu and Angrist (2001) and DeLeire (2000) report evidence of work disincentive effects of ADA itself.

## ESSAYS AND CREATIVE WORKS

### What the Medical Model Can Learn From the Case of the Colorblind Painter: A Disability Perspective

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**Abstract:** The author of this reflection is someone who has lived with hemiparesis throughout her entire life, yet has chosen to work as a physical therapist and professor of neurological impairment within the rehabilitation field. She brings her perspectives to the evaluation of the color-blind painter, whose story was shared in the classic book of Oliver Sachs' *Anthropologist from Mars*. Using the Brandt-Pope Model of enabling-disabling continuum, the reflection begs the questions so often avoided by the medical model, what if fixing the problem is not the sought answer? What if the normal curve has lost appeal?

**Key Words:** Mr. I, cerebral achromatopsia, artist

The case I will present in this paper is that of the color blind painter, *Mr. I*. Based solely on the case description of Oliver Sachs in his classic book, *Anthropologist from Mars* (Sachs & Wasserman, 1996), *Mr. I* was a career fine arts painter who developed a rare condition called cerebral achromatopsia. In this condition, disruption of eye to brain pathways prevents cognitive interpretation of color from otherwise normal, healthy neural signals from the eyes. Even though a person may have perfectly understood concepts of color prior to the onset of the condition, the neurological means to further process visual cues in color are now absent (Heilman, 2003). In cerebral achromatopsia, the person's eyes may still distinguish color contrasts and intensities, but the re-ordered mind can only discriminate and interpret the visual world in shades of gray.

My reflections on Mr. I's story will examine common assumptions of the medical model, assumptions that living with a disability challenges on a regular basis. It will also pose questions that challenge the presumptions of the normal curve, a curve which sees disability only in its fringes, a curve whose presumptions appear indifferent, often ambivalent, about non-normative features of life, including occupation, vision, and ability.

#### Meeting Mr. I at the Juxtaposition of Then and Now

In the following paragraphs, I will first introduce *Mr. I*, and then reframe his case using the disabling-enabling model (*Figure 1*) presented by Brandt and Pope (Brandt & Pope, 1997). Within that particular discussion, I will analyze some of the paradoxical elements of the case, especially in light of traditional rehabilitation notions. Finally, I will conclude the paper with my own reactions to the case study.

Who was *Mr. I* when the story began? He was a successful artist whose world seemed enlarged by the phenomenology of experiential color. He was described as a tall, gaunt man with a sharp intelligent face, characteristics that were seemingly continuous pre- and post-morbid. His fingers were stained with nicotine, suggesting a nervous energy besides. In his adult life, he pursued relationships with the likes of Georgia O'Keefe, an artist who has been described as one

of the great artists of the 20th-century, for her intimately compelling, yet starkly detailed representations of the beauty of the American landscape (PBS, 2006). Like O'Keefe, he too painted in detail, but his dimensions varied from large backdrops for Hollywood sets to small and typical canvases, working the paint with a more expressionistic bent. During his art career, he also worked both as an art director and as a commercial artist. His exposure to and critical appreciation of art was clearly expansive, very physical, intellectual, energetic, diverse, and emotional.

The shift in his story began with a fender bender, and a subsequent headache, which because it represented an impending cerebral vascular accident, a stroke, would turn the tide. From that late 'one afternoon' in time, he emerged as a person with stroke generated acquired color-blindness, a very rare cerebral phenomenon, as most colorblindness is congenital. As introduced above, his cerebral achromatopsia correlates to a deficit in the way the brain translates its visual stimuli into the experience of color (Damasio, Tranel, & Rizzo, 2001). It has no direct connection with the understanding or memory of colors. These attributes *Mr. I* maintained in a strong categorical way. It is also different from a more common clinical problem- color agnosia, in which one's objective perception of color lacks the associative cognition to recognize or name the color.

After the eventful afternoon of his accident and his antecedent or subsequent stroke (this was not entirely clear), he no longer saw the world in its dynamic of living color, but rather in mixes of black, white, and grey, colors associated with anything but vibrancy. He could look at familiar items, especially his paintings, and describe the colors he remembered them to be. The memory files from his countless days of working color into his artwork, his peculiar artist- eye admiration of the world, his appreciation of other works of art, remained. But, suddenly one of the greatest loves of his life- color- was gone-replaced by impressions he found distasteful and repugnant, dirty off-whites and grey black rat colors. The colorful aesthetics he had found endearing in food, faces, clothes, pets, art, and environmental contexts were so severely altered that he, at first, retreated from them.

His life was changed not only in his visual sets, his lost experiences of color, but also in his social life, his expressions of sexuality, and his ability to continue his occupation. He found that this foreign residual gray tone world was neither desirable nor predictable. Black and white films, which would have seemed to offer some familiar solace, lent instead images he could not interpret easily. Some aspects of them were harsh and unwatchable. Additionally, depending on the lighting, he could not find needed objects he sought, including his dog.

#### Meeting Mr. I at the Emergence from Then to Now

As an artist, he was familiar enough with the entire spectrum of colors to commit to memory their detailed reference numbers. Using this numeric knowledge, he began to map his acute experience of the lack of color by descriptively re-inventing his color wheel with his remaining colors as they fit into his known perceptual matters and their phenomenon, the sky and its sunsets, the ocean and its surf. The color wheel that resulted was a working grid of numerically logged and matched shades of greys. This effort connected him to his old world, his remembrance of its living colors, but positioned him in greys, number by number, color by color.

Using his subjective sense of color, he simply re-calculated what he saw of the world. Via this exercise, the blacks, whites, grays, and the tones in-between were no longer simply a lack of color- they were technically identifiable hues. This was important to him, even though he could not see the colors himself. It gave his shaken world stability.

Following his stroke, Mr. I was followed closely by a team of neurologists and specialists who were trying to understand what had happened from a medical standpoint. Because of the rarity of achromatopsia, they felt obligated to test him for hysteria. During that neuro-psychological testing procedure, he could consistently and correctly identify colors by his own exacted schemes, furthering their suspicions that the symptoms were psycho-somatic. At that same time, however, he consistently failed the tests that certain garden variety color blind patients fail. Thus, they were able to rule out hysteria. Even still, their answers about his condition were elusive.

As is common in the medical profession, when in doubt, deference was made to technology. Commonly, the computed tomography (CT scan) or magnetic resonance imaging (MRI) is chosen for diagnostic radiologic study of the brain. In his case, although both means were employed, neither his CT scan nor his MRI were able to provide medically based explanations for why he was experiencing an absence of color in his perceptions of the world, his mental images, and his dreams: why color remained only in his intellectual memory. Sachs describes it “as if his chromatic past had been taken away...totally excised...leaving no trace” (Sachs & Wasserman, 1997).

His early moods, as one could imagine, fluctuated between depression and agitation. His identity, well-being, and competence had been dealt a severe blow. Acute responses to new bodily impairments are real, proving to be disorientating, reactive, and depleting (Williams, 1999). Slowly though, over the course of a year, *Mr. I* moved toward acceptance- acceptance that his condition might not change. With the transitions incumbent upon acceptance, he became very curious and interested in the workings of his own brain. While medical experimentation had offered little to organically change the course of what had happened to him, it did afford a finding or two that lent to small but very significant changes. One finding was that he had his best visual acuity within a green spectrum. With the provided green tinted lenses, *Mr. I.*'s contrast vision was enhanced remarkably and immediately. A sudden acute delight ensued as he discovered a means by which he could enhance his recognition of forms and boundaries. He regained some control over his vision losses.

In addition to this outcome, acceptance also fostered his choice to return to painting again. While the process was explorative and therapeutic as well as artistic, it afforded a familiar environment and context for his rehabilitation process. His early artworks were prolific and extremely intense in their grey tones. His later works waxed more sophisticated and complex. Though his eyes would not be benefactors of any color palette, he eventually even approached the matter of how to insert color into his pictures, experimentally adding various hues to his otherwise grey tone painting. This required a certain passage of time.

While nothing could take away the magnitude and gravity of his loss, not even that passage of time, still, it seemed that as he painted through his loss, the process itself became



pivotal. It seemed to progress him from acute raw desperation to astounding epiphany. He moved from surviving the loss to eventually thriving beyond its void. One of the things that strongly influenced his *clinical* course was the experience of what Sachs described as an *apocalyptic sunrise*. This infused meaning into his visual realities and awakened something in him - a simple sunrise seen differently than ever before. The combination of what he saw and how he saw it- a perspective gained with his own eyes and his own interpretations- represented another turning of a tide. As he afforded himself canvas to express this in re-created images, a whole new impulse and valuation of his way of being took wing. Somewhat deliberate, somewhat intuitive, and very much a part of preserving his art within, he began a reconstruction of his identity. He found new sensibilities and experiences that were contingent on this found world without color.

Little by little he became almost wholly redefined- both by his experience and a certain forgetting of what was lost. With less concern felt for what was behind him, he turned from former orientations, habits, and strategies to find new attributes and assets.

This transformation freed him to actualize his affinity to different characteristics of life than he had previously known. He accepted and pursued his preferences for low light, twilight, and night. He relished the night and found coherence and completeness in it. He redefined his vision not as impaired, but instead as highly refined, privileged, and uncluttered. In the end, when offered a possible cure by his medical team, he found the offer repugnant, unintelligible, and disruptive. He chose to keep his gains in the world of achromatopsia.

This transformation from a life disrupted to one discovered was not kept private or hidden as something stigmatized or unimportant, but instead shared by experts in the medical field, readers of his story, and the audiences of his art. His artwork and his story, through their representation of his different way of seeing, enable/enabled others to find a perspective they might not otherwise know. As members of the “typically seeing” population explored his perspectives, many reported his work to be incredible and inspirational. His renewal as a whole person was clearly personal, but it simultaneously re-constructed the privilege of vision for others to experience vicariously.

#### Understanding Mr. I and His Transformation: What It Offers the Waking World

From the standpoint of the enabling-disabling model, *Mr. I* is first seen as an accomplished artist who, chain smoking aside, was complete within his known world. He could stretch his limits and find no restrictions to his artistic freedom. With the advent of his impairment, the loss of color, his world shrunk for him. It was almost as if the stroke had found his Achilles’ heel. The meanings and definitions of his aptitudes and passions were so integrally related to color, that it was worse than stripping or shrinking (though that is technically the model), it was enlarging his world in all the wrong ways, not making him too big for his surroundings, but too small. Surrounded by wrong, he did not belong anymore. The once close fit he’d known through an intact sense of color changed to distaste, incoherence, aversion, and saddened emptiness. His own reactions together with the abeyance of the medical model’s uncertainties moved him toward a disabling process, a distancing from his inherent strengths and assets, loves, and occupation.

As we look at his transformation from the perspective of the enabling-disabling model, there is clearly a time when he begins to move in a different direction on the continuum, toward meaningful restoration of his person, his efficacy, his competencies, his dreams. His mobilization enlarged his world through environmental modifications, renewed personal commitments, functional restoration and... time.

To begin, we can outline the causes of his limitation as atypical visual impairments with no known cure or correction. We can attest to the further impact of his co-morbid and correlated mental health matters- depression, agitation, and even suspected reactions of hysteria. We can presume that he faced prospective income problems, and with his loss of interest in intimacy with his wife, marital concerns. His initial self-perception of achromatopsia was grave, almost hopeless. His use of the medical field for directives reflected this in its intensity, desperation, and exhaustion. He was a man suspended from the self he had known with no direction back or forward.

The paradox of the story can be seen at once, just by his entrance onto the medical stage: he presents as an artist with atypical color blindness. The medical team frantically reviewed the situation, then the literature; they brought their tests, then sorted through their files of expertise and their medically minded paradigms; there were no clinical pathways for an artist who could not see colors. Without a known cure, the best contribution from all their efforts was seemingly their suggestion that *Mr. I* try green lenses, offered on the basis of sophisticated visual testing. That suggestion proved one of the only enabling contributions borne of a pure medical model's approach to his visual impairment. To their credit, they did rule out hysteria, all the while, offering him assurance that his MRI and CT scan were normal.

The medical professions were quick to assume that news of normal would be a comfort to the receiver, as if the symptoms will be less bothersome, resting on the laurels of such news. Their eventual offer to try to experimentally restore *Mr. I's* color world would seem to be their most noble effort of all to stay true to assumptions of normal as preferable, a pinnacle of modern science. Interestingly, however, by the time that next best thing to a miracle offer came, *Mr. I* had already moved on from what was then to what was now. Just where the medical field had ended its journey, at their patient's choice to turn from a fix, *Mr. I* had begun his own.

For those most comfortable with precepts of the medical model, it may seem strange that *Mr. I* chose not to pursue their heroic endeavors to try to rectify his impairment. They may find it paradoxical that someone would forever give up a world that they had so loved, of light and color. They may question whether such a person could or should really ever forget or move away from the curve called *normal*. They may find that *Mr. I's* validation of his own experience is not real, instead a cop out, a way of hiding his true distresses and regrets. They may question whether anyone besides the impaired *Mr. I* will truly gain from the sharing of his unhealed epiphanies, rather suspecting that any apparent outside interest may be borne of sympathy, not intrigue. They may find it incompatible to consider a loss as window to an enlarged perspective.

But what seems clear from what we read about *Mr. I* is that he did move beyond his impairments, using means that can be elucidated well via identified vectors on the enabling-disabling continuum, (Brandt & Pope, 1997), and by trusting that normal is normal for whoever

defines it. Environmental modification is as important as modifications in a person with impairments. What most enabled *Mr. I* was night time. By accommodating his own visual needs and becoming a night person, he began to feel at home. Another environmental modification was the addition of green lenses. Both of these environmental changes enabled him to make the most of his residual visual function.

The other vector that accompanies rehabilitation is functional restoration. This was accomplished by his eventual return to painting. The agency of his limited vision was incorporated both into his identity as an artist and in his artistic perspectives. It was re-framed as an asset rather than a deficit, described not in terms of loss, but as something found, new, unique, uncluttered, highly refined, and privileged. He emerged as a painter with a new medium, color refined by and defined in its absence. Interestingly, his greatest restorative processes involved no direct modification of his impairment, rather that its features were embraced, managed, used, and studied.

One other enabling-disabling concept is the “symbolic mat”, an undergirding safety net that serves to support a person via social and physical environments (Brandt & Pope, 1997). Pictorially, the more this mat is displaced by the person’s impairments and needs, the less effective it is in lending support. For the mat to support *Mr. I* best, this suggests that he (at least in part) abandon his norms of old. The physical and social environments that best can support him now would necessarily include respect for his new-found works of art, his night time preference, and his own visual perspective. Short of such an environment, he will only experience great displacement of the symbolic mat, equating with a short fall of support. In other words, if asked to function within a world with no modifications, he will almost certainly experience a disadvantage.

The personal journey that *Mr. I* experiences over time- the gravity of loss, his painting through it, his unexpected epiphany, his use of canvas as faith in his new paintings, his forgetting of the past, and his shift to time ahead rather than always looking back were critical to his exploration of what lay beyond normal. His new sense of self-attributions and understandings of grey, his completeness in night-world, and his empowered semantics of refined versus impaired vision were all signs that he felt increasingly at home in his new life. His choice of saying no to a fix of his color blindness ascertained that *Mr. I* did not see himself as a new member of a stigmatized group, not as one less than his former self. In fact, with *Mr. I*’s sharing of his new perspectives with the medical field and his community, one might interpret that his discoveries were highly valued by him. Thus, in his personal journey, he walked away from many assumptions of normal.

In examining the impact of his impairment on his quality of life, it is apparent that he transitioned from a clear functional impairment to a transformed place in which he established a high quality of life within his deficiencies. By entrusting to himself and his vision new understandings and perspectives, he was able to explore and open up countless re-defined possibilities. The trade-off was giving up of the old, then the inevitable and certain neurological forgetting of the past.

His wife and her transformations were not addressed by Sachs, though that relationship likely represents part of the cost of disability. We don't know what it felt like to her to lose what might have been or whether she was even able to grasp his new world, much less with enthusiasm. We aren't told if *Mr. and Mrs. I* stayed happily married or what a staying in the marriage may have meant in terms of her own compromises. We know neither the weight of those things nor whether her relationship with her colorblind mate grew comfortable and familiar, inspiring, or acceptable.

Likewise, even with his successful environmental transformations, won't there still be environmental challenges that *Mr. I* will face each day? Will the environment of the night prove satisfying long-term, non-discriminating, offering the cultural support he needs for his art and his creative well-being? Will his art, more unusual and less commercially desirable, stay satisfying and financially solvent? Will his intelligence and strength transform into eccentricity as his world views perpetuate in a color seeing world? Will his newly created and constructed self-efficacy continue to develop from its infancy forward? Will he cope with his nervous artistic personality in ways that are healthful or will his old habits (smoking in particular) continue a little worse for the added wear? Will *Mr. I* be more naturally inclined to spirituality and life-long learning with his grey scale bias? Will that inclination make up for the likely short fall in other areas? Will he sense the tether of enabling and disabling contexts more as he ages? Will nostalgia for old fits sneak up on him, will he regret saying no to medical interventions toward a cure?

All these represent psychological and social environments that will interact with his person as he ages with achromatopsia. This seems bound to create rocky places and times of self-doubt. His course seems prone to isolation at times, misunderstanding, frustrations, and identity crisis. That there will be on-going dynamics in this case is a given. These dynamics will continue to reverberate within and around *Mr. I*. The course they will take is not fixed. While his story has clearly turned in an optimistic direction from its rough and tumultuous beginning, the metamorphosis described in this paper seems an ironic blend of tenuous and tenacious. Unlike the somewhat wrapped up package of a story of *Mr. I*, the real *Mr. I* may eventually find the world a bit wearisome and it, in turn, may grow less delighted in all that makes him so different from them. His world views may become less palatable to people up close than they are in the comfortable distance of a great story.

#### Parting Commentary from the Peanut Gallery

My reaction to his story comes from at least two and half perspectives. I am an artist. I am also someone who grew up with right hemiparesis, the identical twin to someone without hemiparesis.

As an artist, it is almost impossible to imagine the world without color. I envelop myself in the world's hues. When I recall a hike or a storm, I see it vividly in color. I study faces and the color of eyes. I use colors to describe my moods, even changes I feel in my world view. Color immerses me with larger concepts, coolness, subtlety, fierceness, peace. When I was learning to speak Japanese, I recall discovering that Japanese had but one word to describe both blue and green: Aoi. When I realized this, I could not imagine how blue and green could ever be captured

in the same word. I felt protest. But as I lived there, that protest was overtaken by a warm and wonderful charm. Blue could be bigger and mean more than I had ever considered. That understanding absorbed my preconceived notion of a smaller blue peacefully. It emerged my favorite color in the end and remains so today. It is a consecrated member of a palette I adore. If it were my only color, would I let go of the rest willingly?

When someone asks me what impairment I fear the most, I have often said, being blind. The thought of such a loss can trigger a visceral horror. That is what I felt at the thought of Mr. I's loss, too. Though it was not the complete blindness that I most fear, it was a tortuous blindness. It acted as a thief that stole only the very belongings that *Mr. I* most valued, leaving the rest behind. Left-overs littering the voids left behind by loss of what a person most treasures/cherishes may prove an echoing torment. I related to his struggle to accept what was left of his vision. I truly admire the faith he put in his transformation.

While I cannot imagine how *Mr. I* actually transformed his visual realities, I *can* imagine the transformation that comes to a person as it relates to a physical impairment. Certainly, I have wished that my slow and clumsy right side could feel the dance that sways right and left and twirls without falling, or the rush of skiing down a hill with perfect sense of coordination and control, or the ability to play a guitar with proficient dexterity and skill. I have looked at my twin and wished I had her body for a day. I have begrudged my scrapes and trips and dropped wine glasses. I sometimes have felt that my strong left side was not enough for the dances I would have danced. But because it was enough for the dances I did dance, I am who I am.

As I have matured into who I am today, I can relate to Mr. I and his re-constructionist ways. The attributes I treasure most in myself are intertwined with this profound little impairment of mine. My choice of occupation is an outgrowth of it. I even feel privileged for the perspective having right hemiparesis has lent me including the kindred connection I feel with many of my patients, with left handers, with artists. If given the chance to experience some of the things I always wondered about, I find myself saying, "That might be nice for a day, but why?" Perhaps, had that chance been afforded me when I was young, and I didn't yet know my world through what are now my own experiences, I'd say, "Sure." But part of the world I have known is more whole because of a weak right side. I have grown into it like a vine that is guided by an arbor. I have come to believe that cerebral palsy has gifted me with more wholeness than fragmentation, more meaning than bedlam. I am satisfied that the opportunities and doors it has opened are just alright with me. I like the world where my gained perspectives thrive.

All this said, I both related to Mr. I's story and believed it to be true. It wasn't fabricated as a cheap explanation. The paradox is real, but it is no more real than its counter-part- the very real tragedy of growing up too normal to break free.

Sheryl Holt is a career physical therapist who is currently completing her Ph.D. in rehabilitation science while working as an assistant professor in the doctor of physical therapy program at Wheeling Jesuit University. She has lived successfully with hemiplegic cerebral palsy while serving children with disability for over 30 years.

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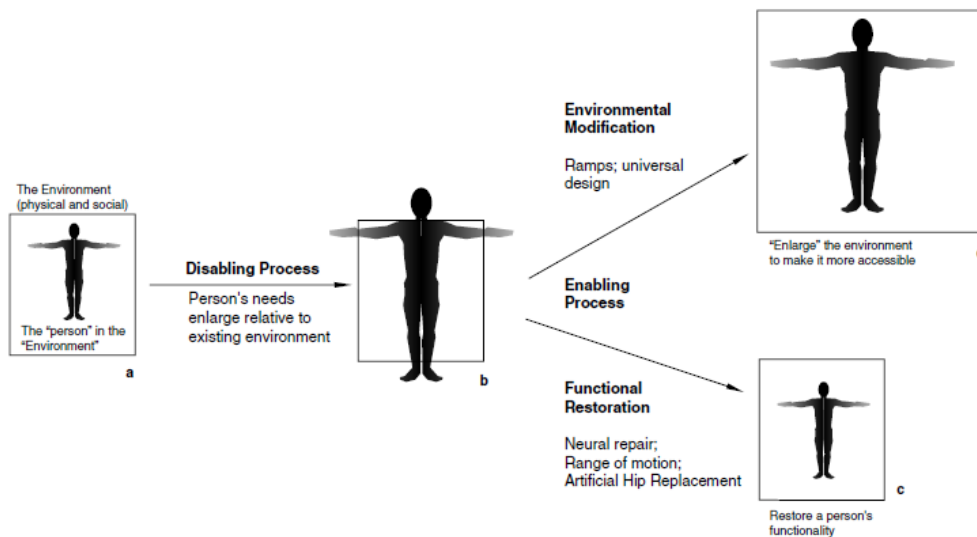
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## Appendix



**FIGURE 1** Conceptual overview of the enabling-disabling process. The environment, depicted as a square, represents both physical space and social structures (family, community, society). A person who does not manifest a disability (a) is fully integrated into society and “fits within the square.” A person with potentially disabling conditions has increased needs (expressed by the size of the individual) and is dislocated from his or her prior integration into the environment (b) that is, “doesn’t fit in the square.” The enabling (or rehabilitative) process attempts to rectify this displacement, either by restoring function in the individual (c) or by expanding access to the environment (d) (e.g., building ramps).

A Brief Commentary on *Health and Happiness*, a short story by Virginia de Forrest  
from *Godey's Lady's Book*, November, 1855, pp. 399-401  
Susan Koppelman, Ph.D.

"Of all melancholy topics what, according to the universal understanding of mankind, is the most melancholy?' Death, was the obvious reply. 'And when,' I said, 'Is this most melancholy of topics most poetical?' From what I have already explained at some length the answer here also is obvious- 'When it most closely allies itself to Beauty: the death then of a beautiful woman is unquestionably the most poetical topic in the world, and equally is it beyond doubt that the lips best suited for such topic are those of a bereaved lover.'"

*The Philosophy of Composition* by Edgar Allan Poe, 1846.  
<http://xroads.virginia.edu/~HYPER/poe/composition.html>

I have been unearthing and reading short stories written by women in the United States or in Territories that later became States since November 1972. I have been thinking about all these stories I have read and trying to think beyond my delight in them to understand what, as a body of literature, characterizes them – if anything. I did not undertake this quest with a notion of what I would find other than my belief that the stories existed and could be found. I believed that if I looked imaginatively enough I would find them. I believed (and feel that the belief is more than justified) that whatever there is to write about, women have written about. I did not presume to predict what themes and issues, which relationships and challenges I would discover to be dominant in U.S. women's short stories. I didn't presume that there *would* be dominant themes or issues or relationships or challenges. I knew I would find stories but I didn't know what I would find out about the stories.

However, over the years, without expecting or seeking it, I began to find out that there were and are dominant themes and issues, relationships and challenges. I have noticed clusters of stories that seemed to belong together, that seemed to constitute a thematic tradition, something that women have written about so frequently that it seems to be a "women's topic."<sup>1</sup> I have published collections of women's stories that extend across two centuries about women's friendships, about battering and resistance, about mothers and daughters, about women and fatness, about betrayals by male partners, about the lives of never-married women, and about Christmas. Illness, aging, and absence of scholarly support have slowed down my productivity but I have quite a number more of these collections in process than I have already published or even written about.

One of my not yet published anthologies is a collection of stories about women and disability and chronic illness. The earliest story in that collection is the 1855 story, *Health and Happiness* by Virginia de Forrest published in *Godey's Lady's Book*. De Forrest wrote it and Sarah Josepha Hale published it. De Forrest, about whom I've found almost too little to bother mentioning at this point in my research, wrote the story. Sarah Josepha Hale, about whom there is now, since the beginning of women's studies in literature in the 1960s, more research than one person would want to consume without some particularly driving interest, published the story. They collaborated in bringing this story urging women to value their good health to what seems to have been the largest possible audience available to any writer in 1855, *Godey's Lady's Book*.

It is the earliest story I have discovered that speaks to the issue of women's health. The story is revolutionary because it speaks in favor of women's health. The story models some of the ways women's health can be pursued. It asserts without reservations that a woman's health and well-being are essential to her and also essential to the happiness and well-being, the health, of her family. The story acknowledges and counters the then-current romanticization of women's frailty and illness. It is quite amazing. The conversations between the ill woman and the healthy woman are conducted with great gentleness. What the sick woman reveals to the healthy woman about sickness and health is done within a class-inflected culture that romanticized the languid woman, the fragile woman, the frail, dying woman that had long been embedded in the popular culture of the day. The sick woman, Emily, declares to Clara, the healthy woman: "Clara, there is no unalloyed happiness without health." Clara responds: "But, Emily, it must be pleasant to be sick now and then, just to find out how much people love you."

Clara expands on the uses of frailty – you can test the love for you of those around you. You can insure their devoted attention if they do love you. There are a number of kinds of manipulation at her disposal, Clara implies to Emily. The complexity, the mineable depths of that exchange could be spun out into a monograph! – if there were any use for it. Maybe someone will think there is a use for it. The exchange is an opening into an understanding of power relationships in married couples of a certain class at a certain time in history. And don't we all know that where there is not equal power between two people there will be manipulation? Of course. And yet Clara doesn't for a minute think she is speculating on ways to be manipulative of a husband she hasn't (perhaps) even met yet. She is thinking romantically. Hmm. What does it mean to think romantically? Emily, with all the understanding and gentleness she can manage tried to apprise Cora of the reality of reality. I can suggest that the reason Emily is so gentle with her young sister-in-law is just that she is a gentle tempered woman. But the more important suggestion is that the young woman represents Hale's readers who have been conditioned by the popular cultures of their day to romanticize ill-health, and it isn't wise to diss your readers. If you want to change their mind about something, gentleness is the way to go. It's a form of saleswomanship.

This exchange about the uses of ill health, during which Emily avers "my cross is . . . ill-health" is the crucial exchange in the story. Emily counters the manipulations Clara suggests are the benefits and the rewards of ill health with what she thinks is even better – the benefits and the rewards of good health. Clara seems unable to imagine that ill-health about which she is speculating as a permanent condition, is a bodily condition and not a performance. She has said, "it must be pleasant to be sick now and then." She seems to think of ill health as something to enhance a woman's attractiveness, like the right color of wallpaper on the bedroom wall.

At the end of the story, after a year has passed, another dialogue takes place between the two women. After long separation during which Emily and her infant daughter Bertha have both undergone major life-style changes in the pursuit of good health, Emily is now well, her infant daughter Bertha is vigorous, the picture of health, and she and Cora are on their way to a reunion of Emily's family. After all that Emily has said to Cora about the preferability of health to ill-health, Cora still says, "affecting an air of languor," "I don't think you and Bertha are half so interesting as you were a year ago; then you both had such white, clear complexions, and were so spiritual; now you are in such rude bloom, and Bertha is positively sunburned."



Whether Clara has learned anything, has had any attitude adjustment, is for the reader to decide. What did de Forrest mean to imply when she wrote “affecting an air of languor?” What do you think? What did de Forrest’s readers think? What were they supposed to think? What did Hale think de Forrest meant for her readers to think? What did Hale think? After all, there is a sense in which this story is not only de Forrest’s but also Hale’s because although de Forrest wrote it, Hale published it.

Sarah Josepha Hale<sup>2</sup> wrote in 1829 that “Physical health and its attendant cheerfulness promote a happy tone of moral feeling, and they are quite indispensable to successful intellectual effort.”<sup>3</sup>

If we had no more information about Hale than that statement, I think we would be safe to think that Hale would approve of the embrace of health and of the equation Emily makes of health and happiness. I think she would want her readers to embrace that equation. I think such an equation might lead to an enormous change in the lives of women in that time and of that class. They would stop using make-up that poisoned them and stop engaging in behaviors that on the one hand was designed to enhance a woman’s attractiveness to a man or to men in general and on the other hand undermined their health and well-being. For instance, cosmetics with arsenic in them. The use of belladonna to create certain optical effects. The wearing of clothing that was so constraining that it led to respiratory problems.<sup>4</sup>

I think the story is absolutely wonderful because long after I read *Health and Happiness* and thousands of other stories, I have retained a sense of it. I’ve remembered my impatience, although I think I understand, with the incredible patience with which Emily addressed her healthy sister-in-law Clara. I just want to snap at that ninny, that romantic childish innocent who is insensitive to the tortured life of her brother and her new sister-in-law. Although their age in years is not very great, their difference in wisdom and understanding makes them centuries, or at least decades, apart. Clara is nineteen years old, Emily, a new mother, just three or four years older than Clara. How thick-headed does someone have to be not to know that life is better, happier, more fun when you are strong and healthy? That little rush of excitement the younger woman gives off because she is part of the great drama of the Dying Of Emily starring Emily and Frank and Clara!!! There is even, for the contemporary reader, a strong intimation of the connection between health and environmental issues! This first story about women and health is as much a story for our time as it was for the mid-nineteenth century.

Susan Koppelman, Ph.D., is a literary historian and independent scholar. She has authored numerous anthologies and analyses of short stories by women, including *The Stories of Fanny Hurst*, *Women in Trees*, and *The Strange History of Suzanne LaFleshe and Other Stories of Women and Fatness*.

#### Endnotes

<sup>1</sup> I definitely do not mean “Woman’s Topic,” an essentialist construction. I mean a topic that women write about a lot, regardless of their race or class or ethnicity or embodiment or sexuality or health condition or climate or region.

<sup>2</sup> For forty years Hale was “editress” (as she preferred to be called) of *Godey's Lady's Book*, which was the most popular ladies’ book of the 19th century. Each issue contained poetry, beautiful engraving, fiction, fashion and manners advice, and articles by some of the most well known authors in America. Although she began editing this

periodical in 1837, she edited another ladies' book, *Ladies' Magazine* from 1828 until 1836. So, as an editor, she was in a position to influence the tastes of American women in fiction and fashion for fifty years.

<sup>3</sup> Park, Roberta J. "Embodied Selves: The Rise and Development of Concern for Physical Education, Active Games and Recreation for American Women, 1776–1865", *Sport in America: From Wicked Amusement to National Obsession*, David Kenneth Wiggins, editor. Champaign, IL: Human Kinetics, 1995: 80.

<sup>4</sup> I could have chosen any of dozens of evidenciary quotations to explain in greater detail what I refer to above as women's self-destructive behavior in the name of sexual appeal. And we certainly needn't go back to the middle of the 19<sup>th</sup> century for examples of this. There are still those who believe that Jacqueline Kennedy's cancer was triggered by the coal tar in her hair dye and today we have self-induced starvation to satisfy an idea of what a woman should look like to be considered attractive.

In the late 18th to mid–19th century, the ultra–pale look persisted. A “lady” didn't need to work in the sun, and therefore should be pale...translucent, even. Some historians even speculate that consumption (tuberculosis) was so common that it became fashionable to look as though you were suffering from TB. Indeed, the white skin, flushed cheek, and luminous eye of the illness was frequently imitated with white lead and rouge. To make the eyes bright, some women ate small amounts of arsenic or washed their eyes with orange and lemon juice—or, worse yet, rinsed them with belladonna, the juice of the poisonous nightshade. More information at <http://www.vintageconnection.net/ModesInMakeup.htm>

## DISABILITY STUDIES BOOK AND MEDIA REVIEWS

### Book Review

Title: *Thinking About Suicide: Contemplating and Comprehending the Urge to Die*

Author: David Webb

Publisher: Ross-on-Wye, Herefordshire, UK: PCCS BOOKS, Ltd., 2010

ISBN: 978-1-906254-28-5

Cost: £13.00 (about \$20.67), 184 pages

Reviewer: Cherie Luckhurst

“If you’ve picked this book up because you are currently thinking about suicide for yourself, then you are the first and most precious audience that I seek” (p. 3). Thus begins David Webb’s book *Thinking about Suicide*. In the quote, Webb sets the tone for the entire work: he respects the sufferer and honors the struggle.

The story is Webb’s first-person account of years of suicide and self-harm. His narrative is balanced with the literature of suicidology and discussions of psychiatric treatments. This book reveals quite acutely the inadequacy of the psychiatric community in addressing the lived experience of being suicidal. Webb recounts instance after instance of marginalization, inappropriate treatments, deception, the dismissal of his thoughts and feelings, and betrayals of his trust. This book is not a protest against psychiatry, but it does reveal a huge flaw in the psychiatric model of treatment in which doctors disregard the lived reality of patient and thereby impede effective treatment. For readers with knowledge of disability studies and disability theories, the idea of treating patients as pieces of broken machinery will be a familiar one.

The book begins with a discussion of the popular myths about suicide. These include: “People who attempt suicide are just selfish or weak. People who talk about suicide are just trying to get attention. People who attempt suicide are crazy” (p. 17), and so on. Webb describes his own perspective: that suicidality is a deep human journey, one that many people travel at some point in their lives. He suggests, “Ignore those who say you are suicidal because you are mad, bad, or somehow broken. Instead, honor the life story that has brought you to this moment, however sad and painful it might be” (p. 3).

Webb then tells his own story, a candid look at the life of a young man who struggled, as many people do, with deep worries and who turned to alcohol and drugs to relieve his pain. The second half of the book is about recovery. Webb gradually discarded the perspective of the medical model. He began to see himself as a whole being who was worthy of respect. He learned to focus inward and discover who he was at his core: a spiritual being who was adequate as he was. This book is no religious tract, though, and Webb does not suggest a church or 12-step programs. He suggests simply listening to one’s internal conversation in a thoughtful and kind manner.

It is frightening to face suicide. Observers struggle to comprehend it—was there a crisis, a death, an accident, a war? Understanding the *cause* of suicidal feelings helps us make sense of the pain. But what if there is no *reason*? What if not even the sufferer knows why they feel

suicidal? These questions are scary, make us vulnerable, and undermine our personal security. Webb offers no relief; he is as baffled by his misery as anyone. Like us, he is confused by his condition, often frustrated with misguided and ineffective treatment, and ultimately unable to find relief for his pain. Yet at all times he is transparent in his struggle.

I found his commentary refreshing and fascinating. I think readers of every type would be engrossed by the journey of this man—from suicide attempts to family intervention to drug addiction to self loathing—and wish for him the best possible outcome. The author does his best to look suffering in the eye and make it speak to him. The book would be an excellent supplemental text in disability studies or psychology/psychiatry, but I would monitor student responses carefully and be sure to provide information for counseling resources. The story is fraught with desperation, blind alleys of treatment, and the author's own feelings of guilt and despair. It is direct in its discussion of the failings of the mental health system, the perils of treatment, and the impact on family, friends, and community. It also considers existential questions that readers may find disturbing.

This book calls for a dialog on the topic of suicidality. In addition, it promotes a treatment model that respects the experience of the individual, instead of suppressing it. Webb confesses that facing his own suicidality took brutal honesty. It is time the mental health community faced suicide with similar respect and candor.

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## Book Review

Title: *Disability and Mothering: Liminal Spaces of Embodied Knowledge*

Editors: Cynthia Lewiecki-Wilson and Jen Cellio

Publisher: Syracuse, NY: Syracuse University Press, 2011

Hardcover: \$39.95; as low as \$20 from external sellers listed on Amazon.com, 348 pages

ISBN: 978-0-8156-3284-9

Reviewer: Carol J. Gill, Ph.D.

Margins, borders, and liminal spaces are the locations and recurrent themes of this book. They compose a geography of transitions and (forgive me) pregnant intersections that, according to editors Lewiecki-Wilson and Cellio, link disability and mothering. Both phenomena encompass dynamic interactions between personal and social, private and public, self and other. Although both mothering and disability are often perceived as matters of nature, the 21 essays in this collection support the editors' claim that there is no experience of the body without culture shaping that experience. It is an important idea, not only because it encapsulates so much of the knowledge conveyed in these essays but also because it gives us hope that current arrangements could be changed ultimately to be more just and affirming of a broader range of humanity.

The book is an effort to expand the literature of feminist disability studies and to enhance the disability consciousness of feminism. Thus, the editors solicited contributions representing multiple disciplines and forms of activism, diverse experiences of mothering and disability (mothers with disabilities, mothers of children with disabilities, daughters of mothers with disabilities, and women considering or refusing motherhood in the context of disability), underrepresented perspectives, and various epistemological approaches (theoretical scholarship, personal narrative, social science research, literary criticism). The essays are grouped into five thematic clusters: 1) Reproductive Technologies in the Disciplining of Bodies, 2) Refusals: Contesting Diagnoses and Cultural Scripts, 3) Narrativity and Meaning-Making: Rewriting Stories of Mothering and Disability, 4) Reimagining Activism: A Politics of Disability and Mothering, and 5) Multiple Identities, Overlapping Borders.

The publisher's website recommends the book to:

“. . . Undergraduate and graduate students in women's studies and disability studies, to therapeutic and health care professionals, to anyone grappling with issues such as genetic testing and counseling, raising a child with a disability, or being disabled and contemplating starting a family”(Syracuse University Press).

To some extent, this volume offers something for all of those audiences. In terms of accessibility, most of the essays are written in a style that should be comprehensible to most undergraduate students, but some essays and the introduction are more abstract and use terms, such as “trope,” “vexed,” and “overdetermined” that may be unfamiliar unless the reader has

some background in critical analysis in the humanities. (Interestingly, the book is physically easier to handle than many books. It is structured to lay flat when opened and allows for fairly easy page turning. Moreover, its reasonable price makes it more economically accessible than many similar books.) Some readers will find the book heavy on discourse analysis and light on analysis of the daily political and economic issues confronting women who live at the intersection of mothering and disability. Others might be disappointed to find that mothers with disabilities are not the dominant voice.

Nonetheless, Lewiecki-Wilson and Cellio have assembled a valuable array of interesting, varied, and original essays that include personal stories, theoretical work, historical writing, diary entries, cultural commentary, and even research reports that convey both the voices of women with disabilities and social analysis of their experiences. I was particularly impressed and stimulated by the editors' introduction and their call for an interactive conversation from multiple perspectives that they refer to as "contrapuntal dialogue" (p. 11), and I appreciated the opportunity to learn from experiences and standpoints that are severely underrepresented, such as the struggles of mothers at the intersection of disability and immigration policies (by Denise Cordella Hughes-Tafen) and poverty (by Shawn Cassiman). I was struck by the creativity, eloquence, and power of many essays, such as Rachel Robertson's beautiful account of developing cultural respect for her autistic son, Ben, in the essay titled "Sharing stories: motherhood, autism, and culture."

In a way, the multiplicity of viewpoints and approaches represented in this collection is double-edged. On the one hand, the pieces are so wide-ranging, it seems difficult to relate them to each other, even when they overlap in content. I found myself looking to the editors to tie some of the strands together in their final chapter but, instead, they offer an annotated list of keywords that avoids defining the terms but rather links them to particular essays, supposedly for further illumination. This conceptual treasure hunt map, though interesting, was unsatisfying as the last word.

On the other hand, the diversity of work presented in the book offers each of us an opportunity to interpret and integrate the essays or parts of them in unique ways that address our particular interests, that raise questions or convey knowledge that is fresh, or that offer new documentation of familiar ideas that we use in our scholarly and activist work. For example, I discovered useful information in unexpected places in these essays and was able to identify themes and questions across essays that might differ from those identified by the editors or the authors themselves. After reading these essays, we are left to apply our own lens to them to determine what they have to say to each other and to us. That seems to be the unavoidable heavy lifting of "contrapuntal dialogue."

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

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

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

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

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