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## RDS EDITORIAL

### Do I Have to Like It?

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

One of the actual problems of being an enthusiastic, “I am disabled now hear me roar” type of Crip is that sometimes being disabled is not very sexy. How to respond when someone close to you says, “But I don’t see you as being disabled. I just see you as yourself.” This is a lovely sentiment during, say, a romantic dinner on a cruise ship, but not so lovely when you fall on your face disembarking from the ship because your special someone forgets that you are blind. How can you respond with enthusiasm in the first instance, when you are glad to be seen as yourself in all of your loveliness, and yet still expect people to remember that there are times when you *want* to embrace your Disabled identity, or simply need their assistance?

I am not talking about the complete strangers who approach you with, “Aw shucks, you don’t *look* or *act* disabled.” These people need to reflect seriously on their prejudices and assumptions and don’t really warrant the space of an entire column. What interests me is the question of, are there times in our daily lives when being Disabled is just not relevant? If I assert myself in one instance as “Loud and Proud,” am I being hypocritical if the next moment I “Just Wanna Be Me” (and that doesn’t include my impairments)?

I remember the first time I felt like I was part of a community of people with disabilities. It was the summer between 6th and 7th grade, and I was attending, for the first time, an Easter Seals sleep-away camp. Up to that point, I don’t even remember actually meeting another person with a disability, and my disability had frankly just been a source of frustration and oppression. My mother and I pulled up to the cabins on the shores of the Hood Canal in Northern Washington State, and there was a group of kids with various disabilities playing an enthusiastic game of volleyball with lots of cheering and humorous put downs. I was like, “Whoa, this is different.” The whole week was like that. I was finally among my peers and to be a member you had to have a disability, which entitled you to forget that your disability existed. Numerous other experiences in my youth and young adulthood encouraged me to simultaneously see my disability as “something to be proud of” and “something that doesn’t matter.”

I also remember the first disability studies text I ever read, the oft-cited *Claiming Disability* by Simi Linton (1998), a book that seemed radical for a twenty-something who had never read the word “freak” with relish. One memorable passage:

“We have come out not with brown woolen lap robes over our withered legs or dark glasses over our pale eyes but in shorts and sandals...We are, as Crosby, Stills and Nash told their Woodstock audience, letting our ‘freak flags fly’...”(pg. 3).

These days, as a faculty of Disability Studies, I spend my days thinking about, writing about, and teaching about disability as a positive identity. I am often called upon to assert myself as Disabled in order to protect my interests. In my profession, and sometimes in my daily life,

being Disabled is a badge of honor. But the fact is that I don't really spend very much time on any given day thinking about *my* disability identity. Most of the time I am thinking about what I will cook for dinner, whether or not it will rain today, whether or not we have the money to go on vacation this summer, how I will get my daughter to do her homework, and how cute I (hope I) look in my new pink Ellen Tracy top and LA Girl almost-black skinny cropped jeans.

In the poem, "Beauty and Variations" (*Disability Studies Reader*, L. Davis, Ed., 2013, pg. 529), Kenny Fries writes: "What is beautiful? Who decides? Can the laws of nature be defied?"

Is it o.k. to "like" it when someone says "I don't think of you as being disabled"? Just as on Facebook, there doesn't seem to be a way to "sort of like it." I think that I have spent so much time trying to make good of my disability that I have forgotten that "identity" is just a way of projecting ourselves in a definable way. It doesn't mean that others who are close to us can't see how complex we really are.

## RESEARCH ARTICLES

### An Ethnographic Study on Religion, Spirituality, and Maternal Influence on Sibling Relationships in a Muslim Family with a Child with Autism

Brinda Jegatheesan, PhD  
University of Washington &  
Klaus Witz, PhD  
University of Illinois at Urbana-Champaign

**Abstract:** This ethnographic study examined maternal influence on sibling relationships when one child has autism. The mother's and typically developing son's understanding of having a family member with autism was shaped by and imbued in their religion. The family's religion and daily practices helped support the child with autism.

**Key Words:** Autism, Sibling Relationships, Religion Beliefs and Practice

Religious and spiritual meanings have been given to disability in many world cultures. Such meanings inform families' understanding of children, parenting, and the nature of relationships between members of the family and the child with a disability. This study aimed to examine the nature of the maternal influence on sibling relationships when one child has autism and how the family made sense of their child's disability. The study used an ethnographic approach. Results showed that the family's Islamic faith was the primary framework through which they understood the meaning of having a child with autism and how to provide support.

Muslim immigrants in the U.S are often viewed as a single ethnic group (Mastrilli & Sardo-Brown, 2002) and their religion as monolithic (Joshi, 2006). However, the Muslim community in the U.S is enormously diverse, consisting of people from different historical, political, cultural, linguistic, and theological backgrounds (Reinhart, 2003).

The ultimate revelation of Allah (God in Arabic) to Muhammad, his prophet, is said to be in the *Qur'an*, the holy book. The Muslim people consider the *Qur'an* a book to guide them on how to live their lives intellectually and spiritually. While the *Qur'an* is considered to be divine, its interpretation is based on the human understanding of its words. The *Qur'an* exists in its original form and language, Arabic. The numerous interpretations are said to be the interpreters' understanding of the holy text and therefore are not considered to be the text itself or a translation of it (Bazna & Hatab, 2005). In Islam, for specific sects of people were teachings on how to live right in one's life.

### Child Rearing Goals

The concept of *Fitrah*, or the belief that children are born inherently good, greatly influences child rearing (Beshir & Beshir, 2004). Mothers are expected to teach their children how to pray, a socialization process perceived as integral towards becoming a good Muslim (Jegatheesan, 2005; Jegatheesan, 2009; Jegatheesan, Miller, & Fowler, 2010). The benefits of teaching children to pray were documented in a study done by Moore (2004). In Moore's study,

young Muslim children begin to learn to recite the *Qur'an* from the age of six or seven, an age group considered to have a “virgin memory” (p. 318) and not yet distracted by the opposite sex. Parents allow their children to observe prayers as early as three years old, helping the children to gradually acquire the skills they need to begin reciting their prayers independently by age seven. Scholars of other Islamic studies have documented similar age expectations for the acquisition of independent praying skill (Miles, 1996; Moore, 2004; Sarwar, 2000).

### Disability in the Qur'an

Islamic scholars who have searched the *Qur'an* for mentions of disabilities have found reference to individuals with physical and intellectual disabilities, mostly in the metaphorical sense (Bazna & Hatab, 2005; Benzahra, 2002). Benzahra (2002), in her interpretation of the *Qur'an*, states that God calls on Muslims to take special care of individuals with disabilities, and that Muslims should not label them by their disabilities. The verses in the holy text emphasize that God made all men equal and that He measures an individual's worth on spiritual and ethical development and not on physical attributes and material achievement (Bazna & Hatab, 2005; Benzahra, 2002). Bazna and Hatab (2005) also found that the *Qur'an* was “consistent with the view that every person is potentially perfect so long as they work on developing their innate and individual qualities to the limit of their individual differentiation” (p. 25).

The *Qur'an* also urges its community members to consider it a duty of every Muslim to provide care, respect, and support for individuals with disabilities (Benzahra, 2002; Gaad, 2001; Morad, Nasri, & Merrick, 2001), and stresses their full inclusion into society (Bazna & Hatab, 2005). According to Bazna and Hatab (2005), the essence of its interpretation on people with disabilities “concentrates on the notion of disadvantage that is created by society and imposed on those individuals who might not possess the social, economic, or physical attributes that people happen to value at a certain time and place” (p. 30). Furthermore, since this “disadvantage” is perceived as “created by society,” the authors state that it comes as no surprise that the holy text “places the responsibility of rectifying this inequity on the shoulder of society by its constant exhortation to Muslims to recognize the plight of the disadvantaged and to improve their condition and status” (p. 30).

To our knowledge, there have been no studies on Muslim families who have children with disabilities. Muslim families in the United States are one of the most seriously neglected groups in disability issues research: not much is known about how their family members come to understand disability and how these beliefs inform parents on parenting and socialization practices (Jegatheesan et al., 2010). The lack of research has been attributed as partly contributing to this knowledge gap (Ali, Fazil, Bywaters, Wallace, & Singh, 2001). Cultural and religious beliefs inform parents about how to raise and socialize their child (Jegatheesan et al., 2010; Shaked, 2005) and parents' expectations of close family members such as siblings (Sage & Jegatheesan, 2010b).

This paper presents an ethnographic study of how Muslim parents begin to construct meaning around disability and how they interpret their child with a disability as a “blessing and a sign from God.” The study also illustrates the realities of the deeper experiences in the lives of the people concerned and in the development of the main protagonists over several years. The

authors focus exclusively on the maternal influence on sibling relationships and especially the relationship between the mother and her developing son as they seek to understand their spiritual experience of having a son and brother with a severe disability in the family. This paper briefly addresses the father-child couple because there was minimal data on paternal influence on the relationship between the siblings.

### Method

This ethnographic study aimed to examine the maternal influence on sibling relationships when one child had autism and how the family made sense of their child's disability. The study was part of a larger ethnographic study that examined how children with autism in three multilingual South Asian Muslim immigrant families were socialized into their society through their cultural and religious norms and values (Jegatheesan, 2005). The first author (ethnographer) conducted 17 months of fieldwork in the home and community environments of the families. More than 700 hours of observation yielded a large and rich data set. This study reports on the Khan family, the only family in the larger study with two children.

Participants included Ayoob and Fatima Khan, their six-year-old son with autism named Jalil and eleven-year-old son named Samir. Parents were in the age range of 30-40 years old and had lived in the United States for approximately 13 years.

### Interviews and Observations

In-depth interviews were conducted with Fatima and Samir. Observations included interactions and communication between the couple (Fatima and Samir) and the triad (Fatima, Samir, and Jalil). Ayoob was also observed when he interacted with both of his sons. Although Ayoob was involved in his son's lives, Fatima played an instrumental role in the socialization of the siblings' relationship. Therefore, the authors focused primarily on the data collection with the mother and her two sons.

The interviews were more like informal conversations using open-ended questions, so the conversations could flow naturally. The first author observed the family and the parents' and son's comments about having a family member with a disability and shaped the interviews accordingly. During the observations, the first author began to notice that religious beliefs shaped the family's understandings of having and supporting a child with a disability as well as the extent of maternal influence on sibling relationships. Interview topics included beliefs about having a family member with autism and sibling relationships, and the socialization of sibling relationships, and reactions and feelings about specific situations that were noted during observations (e.g., How Samir felt when Jalil indulged in autism-related behavior such as lining up objects, preference for sameness, and tantrums).

Observations of the interactions between the siblings and between the mother and her children were conducted at home. The goal of the observations was to document the interactions between mother and children in their daily life and the strategies used to socialize the child with autism and sibling relationship. Keeping this in mind, the first author observed interactions over

different days of the week and at different times at home and in the community. Observations were video-recorded with permission of the parents.

### Analysis

The analysis process involved grounded-theory analysis of the entire data corpus of narrative episodes, dialogues, and conversations (Charmaz, 2002; Glaser & Strauss, 1967). Since data analysis was inductive, codes were not established prior to the interviews and observations but instead generated from the data. Transcripts were reviewed repeatedly and systematically by the authors who coded for initial themes and developed a working definition for each code. These were iteratively evaluated against the data and against the two authors to ensure rigor in interpretation. Using the constant comparison method (Strauss & Corbin, 1990), codes were organized into categories. Themes emerged as the authors engaged in repeated discussions and reflections of the categories. The themes were continually cross-referenced with the narratives to ensure that the themes were consistent and grounded with the data.

The results of the study are presented in the form of an ethnographic case study in eight sections. The organization of the sections is explained at the end of section 1.

### Findings

#### 1. Background - the Khan Family

The Khan parents are multilingual immigrants from South Asia. Ayoob was the sole breadwinner of the family, and Fatima was the main homemaker in the house. The family prayed five times a day at home and in the mosque, fasted during Ramadan (the Holy month), and sent their children to Qura'nic schools. Elders in the family often prepared to take the journey to Mecca. Fatima frequently read to her sons from children's Islamic books on how to live right.

Samir, the family's other son, was an 11-year-old boy who liked to play sports and computer games. He was born in the United States. As the oldest son in a Muslim family Samir was expected to be understanding and accommodative of his brother's needs. Samir attended a neighborhood public school and during weekends attended a Qura'nic school. His younger brother Jalil was 6 years old. Around the age of 29 months, Jalil began to show characteristics of autism such as sudden loss of language, and preference for being alone. Final diagnosis was made at age three after consultations with pediatricians and psychiatrists. At the onset of the study, Jalil was non-verbal and used gestures to communicate. He attended self-contained classes for children with autism in a public school and received sporadic therapy services.

The following ethnographic study first sketches the evolution of Fatima's (the mother's) subjective response to Jalil's autism (section 2). Fatima went through some of the typical upheavals before diagnosis and when diagnosis became certain. In time, she formed an understanding that Jalil was a special child sent to her and her family by Allah. From that point on, she started sharing her new understanding with Samir. Much of the study becomes a story of their constant interaction and eventual team effort in dealing with the numerous situations caused by Jalil's condition. The remaining sections (sections 3-8) focus on Samir, but always keeping in view his interactions and relationship with his mother and his brother with autism.

## 2. Fatima's Initial Reactions to Jalil's Diagnosis of Autism

Fatima went through some of the typical reactions of parents who realize their child has a significant disability (Goin-Kochel & Myers, 2005; Hutton & Caron, 2005). Soon after diagnosis, many relatives often expressed superstitious beliefs that they believed harmed the development of Jalil's brain. These superstitious beliefs concerned maternal behavior during pregnancy such as stepping out during the eclipse, attending large and noisy community gatherings, and maternal diet. Stepping out during the eclipse was perceived by orthodox elders as a bad omen that affects the fetus, causing illness and/or disabilities. Similarly, would-be mothers attending crowded and noisy events were considered to be harming the child because exposure to such environments "disturb, alarm or shock the fetus," leading to brain damage. Lastly, in terms of maternal diet, Fatima reported that she craved for and ate a lot of goat's brain during her pregnancy, despite being advised against it. The brain of the goat has numerous intertwined nerves and as a result of Fatima's consumption of this prohibited food, Jalil was believed to have developed similar brain patterns leading to malfunction of his brain. These beliefs were openly discussed at family gatherings. Fatima said that she felt guilty and sad when she heard these explanations. She found herself wondering if she had not righteously conducted her life. Fatima went through a period of intense questioning about her own life and actions. She said, "I asked Allah, 'Why we get him like this? Why we deserve this,' or I used to ask my husband, 'What did we do wrong to have our son become like this?'" Ayoob discounted the superstitious beliefs and said there must be a deeper explanation. Fatima's mother-in-law thought that Jalil was *phir baba* "holy boy" and told Fatima that perhaps Allah has a plan for her, and that she should ask for an understanding of her son's condition in her daily prayers. In time, Fatima came to accept that she had not committed any sin. She quietly "accepted my son as a gift..." sent to her "directly from God." She called it fate and said, "I was okay because God gave us like that. He has a plan and I don't know what it is. He will make him okay or not, that is whatever God wants. It's not up to us." Fatima explained further:

[1] Fatima: Now I have His special child, I need to know how to do everything for him. And so I prayed for God...I pray everyday and ask *Allah* to be with me and help me be a good mother to Jalil. God was listening because I feel better and have new energy and courage to try new things. I was not afraid. So that's why I am like this now. My husband says I am changed.

Ethnographer: Changed?

Fatima: Yes! He says I have become strong...I am not like, before, when I would say, "Ah, okay, let it be or what can we do? Now I am like, "No Jalil can! And he will if we believe in him. Anything Samir can do, Jalil can do it also!" So, for example, last year [2003], the public library had a children's Summer Reader's Award. Children had to read 25 books and retell the story to the librarian in the library. Samir got the award. I am seeing how Jalil is looking at his brother's award. And I feel sad. That evening, I said to my family, Jalil can get the award too! Everyone at home thought I had gone crazy. Next day, I went to the librarian and said, "My younger son has autism and he wants to try for the award. He can read but he cannot retell the story on his own. But he can retell the story through 'questions and answers.' So, if you ask him questions about the book, he will answer those questions. That way he will retell the entire story. And Jalil did it. He



read 25 books in summer time and got his award. And the whole family was so happy... I don't accept that my son cannot do something. I believe in my son and I know that *Allah* will be with him and he will be okay. I must give him the same opportunity as his brother. I am seeing how Jalil is happy with his reading award.

Fatima felt that her prayers continued to be answered. Her husband commented often that she became very forward in advocating for Jalil and had become very confident. She added that prayers were her greatest source of comfort and help. She said, "In my prayers I asked for God's guidance. I asked, "How I can do things for my son, now he has this disability, still what more I can do for him? I want to try everything, I will keep trying everything."

"Trying everything" for Fatima included learning about how to parent her son with autism through reading books and websites on autism and getting a diploma in child development, being actively involved in her son's schooling and therapies, and ensuring that Samir was learning how to support his brother. Fatima involved and engaged Samir in helping Jalil overcome behavioral challenges, learn his school work, become competent in his communication, and teach him prayers. In this manner she pursued her feelings that she had religious duty to effect improvement or even a cure as the response to this God's given challenge.

While people at the mosque and the Qura'nic school did not have knowledge of autism and how to support a parent with a child with autism, they were, however, supportive of Fatima's desire to make sure that her son learned his religious duties. Fatima explained that although Jalil was the first child with autism in the Qura'nic school, the staff and teachers were accepting and supportive. She said:

"The principal of the *Qur'anic* school accepted Jalil even though autism was new to him. He had not seen a child with autism. Nobody had a child with autism in the class. And Jalil showed all the symptoms of autism like hand flapping, saying some garbled sentences over and over again. But they understood how important it was for me to help my son learn his prayers, learn Arabic and be in this school. They were supportive of my wish to sit with him in his class all the time to help him learn and help in the classroom if he does something that the teacher does not understand."

Informal conversations between the author and the Qura'nic school teachers revealed that Jalil was viewed and treated just as any other child. Teachers admired and respected Fatima's aspiration and perseverance to teach her son his religious ways. Jalil was frequently observed to be stubborn and indulging in repetitive behavior during recitation lessons. But teachers continued to be patient with him. Inaaya, Jalil's Arabic teacher, explained her views on supporting Jalil to learn his prayers even though he had problem behavior:

"He is special but he is also *Allah's* child like all others are. And his mother brings him to learn to pray even though he has a disability, and I think that she is amazing to do this. It is my duty to teach him however much he can learn. *Allah* knows the child's heart is pure."

### 3. Mother's Teachings and Samir's Early Responses to his Brother having Autism

Fatima shared her thoughts with Samir that Jalil was a special child of *Allah* whom *Allah* had made that way and that their family was the special family that *Allah* had chosen for Jalil. The Khan parents felt that if a child like Jalil were to end up in the wrong family he might suffer.

[2] Ethnographer: When he asked at that young age about why God sent Jalil to this family, what did you tell him?

Fatima: I tell Samir that *Allah* gave him to us because He knows that we will take care of him, teach him and not get angry and mad. I tell Samir not to compare his brother to him and his cousins. I tell him there maybe some things that his brother might do one day that he himself maybe cannot. We must believe in Jalil, believe in *Allah*. Samir is a good child. He understands.

For the Khans, being the special family involved both loving Jalil and taking care of his needs, teaching him, and practicing high standards of self-discipline and behavior for *Allah*'s sake. Family conversations about Jalil were of the following nature, “[*Allah*] knows that we will take care of him,” and “*Allah* wants to see that family members and Samir do not get angry and mad.” Fatima herself developed an awareness of Jalil as a special person in his own right rather than just a person with a disability. She said she believes that “there may be some things that Jalil might do one day that Samir maybe cannot.”

Fatima described Samir as a good child who listened to her and was empathetic of his brother's disability. The following account of an observation illustrates how Samir helped Jalil in a mature manner, sacrificing his opportunity to play with his cousins:

[3] Six children were playing in the computer room. They were trying to encourage Jalil to be part of their game. Jalil became fussy, and whiny and did not want to play with them. .... When his cousins called out to him to come and play with them, he whined louder, and became visibly upset. His cousins turned to their own play and Jalil withdrew into a corner of the room, self-stemming himself. Samir kept glancing towards Jalil and then got up and went across to him. He sat by his side and put his arm around him. He asked him if he wanted to come and join him. When Jalil shook his head in negation, Samir asked him if he wanted to play something else. Jalil sniffed, wiped his nose with the back of this hand, kept fidgeting with his toy car and pointed to the computer. Samir took his brother's hand, led him to the computer and set the computer game for him. He stood for a while by his brother's side and watched him play frequently glancing towards his cousins playing, since he too wanted to play with them.

When the ethnographer a little later asked what Samir felt about his brother and what he felt about his brother's disability, he said:

[4] He is still a human being. He is different but we are all different. He is different because *Allah* made him that way. Maybe we all have to learn from him something that we cannot learn without him. He has a lot of changing in his behavior to do. But even

though he is so bad like screaming for the computer, he is not a terrorist. He does not hurt anybody or make anyone cry.

When asked about how he first reacted when he learned that his brother had autism Samir reported that he had wondered about the changes in his brother prior to his diagnosis. He said that he noticed that his brother “acted weird” and “screamed sometimes like he was mad about something” and he was increasingly “getting upset.”

[5] Samir: He was not the same suddenly.

Ethnographer: Not the same?

Samir: Yeah. Like he would shout and not tell us why he was angry. Or only open his mouth, make a face like sad face and not talk.

Ethnographer: So you were surprised.

Samir: Not! It was happening a lot. I asked him to say why he was mad at me and he would get more mad. He was not saying anything.

Ethnographer: What did you think?

Samir: Nothing. I got mad also.

Samir stated that when he first heard the word ‘autism’ during a family conversation, he did not think much about it and soon forgot. But Jalil’s language regression made his mother worry a lot. For the first six months, Fatima was the only one in the family who was convinced that something was wrong with Jalil. Her husband and his family told her not to worry, explaining that “boys speak late.” Samir witnessed his mother’s increased anxiety and in time he observed how once his mother convinced his father and grandparents, she scrambled to get an accurate diagnosis and make sense of their son’s condition. Samir shared a turning point experience:

[6] I became mad one time. It was my turn on the computer and Jalil kept pulling my hand and pointing for him to sit. I refused and he got mad. Then he ran down to my mother and began to cry. My mother came upstairs and told me to give him the computer. I was mad and told her he had finished his turn and now its mine. She asked me to get up and give the chair to him. I was mad at my mother and my brother.

Ethnographer: .... Did your mom say you were a good brother?

Samir: She talked with me and told me that Jalil is like that because of autism. It does some things to him. She told me that we should understand the autism and what it does. We must help him and not get mad at him.

Ethnographer: So your mom told you everything?

Samir: She told me that we must find out more and that I can help her to understand autism more. She said then if we understand autism we can help my grandmother, aunt and uncle understand it too. My mom said if we are helping Jalil, then others will see that and do the same. If we are mad, then they will be mad.

Ethnographer: Oh. Like be a good example.

Samir: Yes. So I found out more from the internet and my mom got some books.

Fatima had enlisted Samir as her and his dad's ally in trying to help Jalil, and by getting more information and a more detailed understanding of autism they could possibly help the other family members.

#### 4. The Family Learns Together About Autism

Fatima told the ethnographer that once Samir began to understand autism (as described in [6]), each day brought new insights to the two of them. Mother and son often talked about each other's new insights about autism over an activity such as doing a puzzle or drawing with Jalil. As parents, whenever Fatima and her husband found out more about autism, they would talk to Samir, so that he would understand why his brother was changing. "Samir and Jalil are playing together and Samir must understand why sometimes his brother is difficult," she said. Fatima reminded Samir that Jalil was sent by *Allah* because their family would take care of him and not be unkind to him. She told him, "He chose you to be his brother... In all the world, He made you and him brothers. So you have been chosen by *Allah* too."

Fatima reported that Samir on his own started reading and learning about autism and ways to help his brother, but she was not aware of the deep effects the new orientation had on him until about half a year later when she talked to his teacher. The teacher showed her a copy of the New Year's resolution [7] Samir had written in creative writing class at the beginning of the semester. This was a few months after diagnosis, when Samir was about 9 years-old.

[7] Creative Writing.

January 11, 2001

In the year 2002, my New Year's resolution will be helping my little brother speak since he doesn't know how to speak. He is a kid who is autistic. "Autistic" means can't speak. I'm going to try to make my brother speak.

Fatima had brought a photocopy of the writing to share with the ethnographer.

[8] He is a good child. I sometimes get upset thinking he is not patient enough with Jalil... He is thinking a lot about his brother and autism. I can see that in this writing... In his own way he is learning about his brother and how to help him... I was so proud. When I asked him about the New Year's resolution, he said that he is going to try very hard to help his brother because he now understands a lot about it.

The creative writing example shows that Samir was independent in taking charge of his portion of the task in helping his brother. When the ethnographer showed him the copy and asked him why he wanted to help his brother to "speak," he replied:

[9] If he can speak, he can tell me what he wants and I can help him. If he is afraid he can tell me, if he sad or mad he can tell me.

Ethnographer: And that's important, Samir?

Samir: (nods in affirmation).

Through Samir's conversations with his mother, the ethnographer learned that the learning process of autism was a shared family endeavor. Part of the endeavor involved telling Samir to "help," "be patient," and "not complain" about his brother. Fatima told Samir that "complaining will not change Jalil." She also pointed out that "Jalil was unable to complain about his needs that were not met and his frustrations." She told Samir, "We then must put him first by understanding him and being there for him. Not give in all the time, but be patient and help him." The ethnographer asked Samir how he felt about this.

[10] Samir: I don't know. I think about the autism and why Jalil had to get this. My mother said that my brother was not different because of autism but some people think it is like that. So we must learn more to understand Jalil. That's what I am doing.

Ethnographer: Such as...

Samir: Like I look in the Internet. I read about it. I look at my brother and see how he is different. So it's not difficult. He cannot speak now. But he can still communicate with his hands like this (gestures). So I must try to understand some new things to help him.

Ethnographer: What new things? Do you do some new things?

Samir: In my prayers I now ask *Allah* to help him be a good boy. Its new thing when I pray. My mother said we should all pray and he will be better in the future.

## 5. Deeper Communication

Samir was observed to be deeply empathetic regarding Jalil's needs. The ethnographer often recorded that Samir went the extra mile to accommodate his brother. There were the occasional disputes, mainly over the use of the computer games. Samir was found to be tuning into his brother a lot and would often inform the ethnographer of particular things about Jalil. For example, he would tell her without her asking, "He likes to watch himself in the mirror and this time is best to talk with him because he responds," or "It's 30 minutes now and his computer time is up. Now he will call so sweetly, (in a sing-songy voice) 'Samir, oh Samir. Come Samir, oh Samir.'"

[11] Ethnographer: Why does he say so many times like that?

Samir: Because he is smart. He knows that I will say, okay another 10 minutes because you called me so nicely. He is not stupid. He is smart. I watched him and he knows he can get what he wants from me if he is nice.

Ethnographer: So you know.

Samir: Yes, I watched him and also told my mom about this.

Ethnographer: Isn't that real smart of Jalil? Wow.

Samir: He is more smarter. I am now seeing this more each day. I am watching him carefully.

Excerpt [11] shows that Samir's whole understanding of Jalil has changed. At first (2-3 years ago), when Jalil cried, Samir did not know whether he really was crying or whether he was faking, but by the time of the conversation [11] he was very much in tune with him. He knew that his brother was faking, and Samir talked about this with humor. A few months later, the ethnographer recorded the following observation fieldnotes.

[12A] The two brothers were playing and then the car wheel broke. Samir spent 30 minutes trying to fix it for Jalil, who was teary about the broken car. During this time, I saw no verbal communication between the brothers. Samir would tap Jalil to reassure him, nod, and give him glances.

Afterwards the ethnographer asked Samir about this silent interaction.

[12B] Ethnographer: How did you know what your brother felt because you guys said nothing.

Samir: I usually know. I listen to him, actually, I look at him and then I know from his face what he feels. It is pretty easy.

Ethnographer: And you did not want to say anything to him?

Samir: No, it will make him more upset. And I don't want him to cry. Then my mother will get mad at me because she thinks that I made him cry.

Ethnographer: Oh.

Samir: But also my mother said to me that if I listen carefully I can understand what my brother is feeling.

Ethnographer: Listen to what?

Samir: To him. Like he is sitting and I listen to him quietly. He can tell me with his feelings.

## 6. Feeling Others' Needs

Often Samir was requested by his father to do simple tasks for his brother (e.g., tie his shoelaces, bring his coat, peel a banana). His father bestowed a lot of affection (hugs and kisses) on Jalil. Relatives at home also showered Jalil with tremendous amount of affection, and Samir was observed to quietly watch the love that surrounded his brother. Fatima was observed to be the only person who paid equal attention to both her sons.

When the ethnographer asked Samir what he felt about "so much of attention on your brother, everybody wants to hug and kiss him," Samir responded in a mature way that he knew Jalil gets a lot more attention and that he understands and feels it is important to let Jalil know that "everyone at home loves him."

## 7. Communicating with God through Prayers

The family put much emphasis on both children participating in the daily prayers. But the ethnographer saw Samir talking about *Allah* as playing a big role in Jalil's behavior. This behavior is illustrated by the following observation in Samir's bedroom as he taught his brother *Du'as* (short prayers). Samir was encouraged by his parents to teach his brother *Du'as* and *Surahs* (verses from the *Qur'an*). Samir took this responsibility very seriously:

[14] Samir: time to say your prayers Jalil.

Jalil: [No response.]

Samir: (taps on his arm) Time to say *Surah Fatiha*. Come on, its time

Jalil: (hits his hand off his [own] arm and screams a little).

Samir: Okay, I am going to say it and you listen. Okay Jalil. Its good for you to at least listen. You don't have to say it. [Begins prayer:] *Bismillahir Rahmanir Rahim Alhamdu Lillahi Rabbil 'alamin.*

Say Jalil, it's good for you. You can say it softly okay.

Samir: *Bismillahir*

Jalil: *Bismillah*

Samir: *Rahmanir Rahim*

Jalil: *Rahman*...blender, it's a blender. I got a blender [starts to go off into autistic-like echo]

Samir: *Rahmanir Rahim*, say like this. *Rahmanir Rahim.*

Jalil: Whoosh, blender. I like the blender. Whoosh, whoosh.

Samir: Okay say it in English. *Allah* please forgive me

Jalil: *Allah* please forgive me and make me a goooooood boy.

Samir: Very good. *Allah* will make you better.

There are several noticeable elements about the above exchange. Whenever Jalil did not respond appropriately, Samir was unruffled and patiently adjusted his efforts a little, demonstrating care and intimacy with brother (taps him on the arm, "Okay, I am going to say it and you listen .... You don't have to say it" "You can say it softly okay"). At the end, when Jalil said one line spontaneously expressing his own feeling, Samir was completely satisfied: "Very good. *Allah* will make you better."

Over a period of time the ethnographer watched similar interactions of Samir's showing tremendous patience in teaching the *Surahs*. During this time Jalil would romp around and jump on the bed, or hop over the bed from side to side and making faces in the mirror. Samir, in the same tone, with the same gentle persistence would try to get his brother to repeat the *Surahs* after him. He would follow him around the room as he coaxed him. One day, his mother walked in and caught Jalil jumping. She wrapped her arms around Jalil and said, "Listen to your brother! Now say what Samir is saying or NO going to see Rudy (neighbor's dog that Jalil loved)." After the second such observation, the ethnographer talked to Samir about his patience and tolerance.

[15] Ethnographer: What about when you teach him his prayers. You have a lot of patience, Samir. Sometimes, I noticed that Jalil is very playful and he will not do it.

Samir: That's okay. *Allah* understands because he is special. I must try and not give up.

Ethnographer: Not give up. Who told you that?

Samir: My mother. She said that I must try hard to teach him to pray. I tell my brother what to pray.

Ethnographer: Like what?

Samir: Pray for cure. For forgiveness.

Ethnographer: Forgiveness for what?

Samir: I don't know. Maybe he did something and he must now ask for forgiveness and then he will become okay. He must ask *Allah* to forgive him.

Ethnographer: Is that WHY you want HIM to learn to talk?

Samir: One reason. I have many.

Ethnographer: Can you tell me?

Samir: Like I want him to play with me and not scream loudly if he wants something. Sometimes, I pray to *Allah* for making him alright because he gets mad and screams. But there are other things also. Like I want him to tell me if he had a sad day. Then I can help him. I can understand him better when he cries. Now, I don't know if he is crying for fun or he is serious. Sometimes he plays a joke on everyone by faking it.

Samir then explained why it was important for Jalil to pray.

[16] Samir: We are praying everyday to *Allah* and I think *Allah* is listening to us. He is making him smarter and He is showing us in this way. I tell Jalil to pray and he is doing that now.

Ethnographer: So you think that Jalil is getting smart because you are praying for help.

Samir: Yes, but he must try too. It is good for him. He must ask. It can be a whisper but he must say his *Du'as* too. *Allah* will listen to him.

Ethnographer: You are sure?

Samir: Yes. He is better than last year. So it means he is getting better.

## Discussion

### Superstitious and Religious Beliefs and Biomedical Explanations on Disability

The Khan parents endured substantial stress and anxiety in understanding the cause of their child's disability after a period of typical development. Medical and allied health professionals were frequently reported as being unsure about the cause of autism and frequently dismissed parent's persistence in receiving an accurate explanation of the etiology of autism. Professionals were also reported as using extensive amount of medical jargon in their conversations, complicating the Khan parents' ability to think clearly and fully comprehend their child's condition. Ayoub and Fatima described this period as long, traumatic, and confusing and soon began to search for an understanding of their child's disability on their own.

According to Fatima, superstitious beliefs that circulated in the family circle contributed to her having "bad feelings and reservations" about having a child with a disability. The prevalence of superstitious beliefs has been documented among individuals across cultures (Lamorey, 2002). However, Fatima, after having risen above superstitions beliefs, developed a spiritual understanding of why she had a child with autism.. She attributed her new understanding to her husband and her mother-in-law who believed in a religious explanation. She added that she also went through a period of questioning her life and thought about her actions and habits and came to an understanding that she had not committed any wrongful deeds that could have harmed her son. She then accepted her son as a blessing and from then on developed a deeper and fuller spiritual understanding of having a child with a disability. In a study of parents' lay conceptions of autism (Gray, 1995), parents went through similar experiences, where the absence of explanations for the cause of autism led to them developing their own understanding of the disability, and in doing so achieved partial emotional closure. For the Khan family, although they were exposed to some medical explanations, the spiritual and religious explanations dominated their conceptions of having a child with autism.



Fatima had a theological belief that God had a plan for her and sent her a son with special needs. She reported that “acceptance” of *Allah*’s wishes were foremost and sought strength and guidance through prayers. Through continuous worship, she worked on building a bond with God to guide her in parenting her special child. Fatima’s fatalistic belief that “God will make him okay or not, that is whatever God wants,” was also viewed as being hopeful for a cure if God wishes. Fatima believed that her responsibility was to be a good parent and being a good parent included “trying everything” for her son and fulfilling her religious duties. In prayers, she asked for the presence of *Allah* in her life, for guidance on being a “good mother,” and to give her “new energy and courage.” She saw praying for a cure as part of continued effort of “trying everything.” Similar fatalist beliefs and the importance of striving for the better have been expressed by Islamic general practitioners in Yamey and Greenwood (2004). The authors report beliefs of Prophet Mohammed, who was to have said that ‘for every illness, there is a cure, except one, and that’s old age’ (pp. 457). Participants in their study believed that seeking medical help for recovery was part of their striving to do things for the better. Fatima was relentless in her effort to “try everything,” including asking for a cure in her prayers to *Allah* and then leaving it all in God’s hands (“God will make him okay or not is in his hands”).

#### Relationship Between Fatima and Samir – Helping to Understand a Brother with Autism

Fatima supported her typically developing son in understanding his brother with autism. She provided him with whatever information she had about autism, urged him to have a caring and compassion attitude through the teachings of Islam, and placed him in a teacher’s role, such as teaching his brother prayers. She also used conflicts between the brothers as teaching opportunities to provide Samir with guidance and feedback about desired and undesired behavior. Samir, in time, began to make connections with his brother, on each occasion, after much introspection, making changes in his interaction style. With an increase in the understanding of autism, conflicts between the brothers decreased substantially.

Fatima and Samir had very open communication about autism, its challenges and uniqueness. Increasing an understanding of autism was a shared endeavor with this dyad. On a deeper level, Fatima was the guiding light for Samir and began to inspire Samir on the spiritual realities of having a brother with autism. She frequently conveyed to him the richness of human experience and encouraged him to take a spiritual journey of discovering the essence of his brother. Soon he began to uncover, in bits and pieces, what it means to have autism, looking at it from the perspective of the one with the disability.

#### Unity and Team Spirit between Fatima and Samir – Reaching Out to Jalil

Fatima and Samir were a vitalizing force on one another, resulting in an evolving relationship. Sometimes Fatima was the one who knew a lot; at other times she would search on the Internet for information about autism, as did Samir, thus making them equal partners. Together, they sought to improve themselves constantly, to find new and innovative ways to reach out to Jalil, sharing experiences and strategies that were effective as well as their hopes, anxiety, and admiration for even Jalil’s smallest achievement. Fatima worked hard to educate her typically developing son and strived to fill Jalil’s environment with love, compassion, and encouragement. She made sure that Jalil had the same opportunities (e.g., reading competition)

as his brother, ensuring that Jalil could manage even the toughest of tasks (e.g., getting the Summer Reader's Award, participating in a *Qur'an* recitation competition) as long as he had appropriate support. Fatima's religion urged her to keep an upbeat spirit and do all that she could to help her son with autism.

### Recommendations

Fatima would have found beneficial being connected with other South Asian parents of similar cultural and religious backgrounds who have children with disabilities. She would have been able to share her everyday experiences of raising her sons and at the same time hear the stories of other parents in her circle of support. Particularly, at the time when Fatima was experiencing guilt and sadness because family members attributed her behavior during pregnancy as having caused her son's disability, connections with other parents could have been an important source for emotional nurturance and comfort.

Similarly, Samir could have benefited from being connected with other children who have siblings with autism, especially when he was trying to understand his brother's symptoms. Siblings of children with autism often assume the role of mentors and provide help on an ongoing basis (Benderix & Sivberg, 2007; Cuskelly & Gunn, 1993; Stoneman, 2005) and have been found to silently endure feelings of uncertainty and worry (Sage & Jegatheesan, 2010a). Particularly in Asian families, older children are often expected to demonstrate altruism in sibling relationships (Braun, 2008; Sage & Jegatheesan, 2010b). Samir would have found sibling support groups as a place to share his concern and emotions with peers who are in a similar situation. Being a part of a sibling group during these difficult times would have been greatly beneficial to him.

Finally, this study shows that the mother's faith played an important role in her understanding of why she has a child with autism. The mother's faith informed her child rearing beliefs and practices, and duties towards the child. The mother's Islamic faith also helped to buffer her anxieties during difficult times. A deeper understanding of the impact of religion on a family's comprehension of disability and their relationship with the child with a disability should be known to all professionals who work with culturally diverse families and their children with special needs.

**Brinda Jegatheesan, PhD**, University of Washington, researches the role of religion, culture and language in the development of children with disabilities and their learning across various home and community settings. Questions regarding this study should be sent to Professor Brinda Jegatheesan, Department of Educational Psychology, College of Education, Box 353600, University of Washington, Seattle, WA 98195. Email: [brinda@uw.edu](mailto:brinda@uw.edu).

**Klaus Witz, PhD**, has interests and publications in the areas of cognition, philosophy of science and education, religion, spirituality and the self. He is the author of, *The Supreme Wisdom of the Upanishads: An Introduction* (1998).

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Background Social Structures and Disability Discrimination  
in the United States and Canada

Mark C. Weber  
DePaul University

**Abstract:** Several social structures deeply affect the equality of people with disabilities, but are not ordinarily considered when addressing attitudinal and environmental barriers that disadvantage disabled people. These structures, which relate to employment and the law that regulates it, are: (1) the legal doctrine of employment at will as opposed to notice or severance payment in lieu of notice; (2) unionization or its absence; and (3) government-sponsored social insurance programs. These structures differ from country to country, even between nations with a similar legal heritage. Drawing comparisons between Canada and the United States with regard to each social structure, this paper describes these arrangements and their impact, then discusses how their reform could enhance equality for people with disabilities.

**Key Words:** social model of disability, employment law, comparative law – Canada and United States

Social structures affect opportunities for disabled persons to participate in society as equals. Social structures are the stable systems by which people or groups relate to each other (Bell, 1965, p. 208). Social structures such as the way buildings and streets are constructed, job qualification standards, educational opportunities, medical care systems, and popular culture either engage or marginalize disabled persons (Hahn, 1993). Some of these, notably building standards, public transportation systems, and education, have long been recognized as disadvantaging people with disabilities, and activists have targeted them for change (Berg, 1999, pp. 9-10). Activists were working to alter physical and attitudinal barriers in these areas long before the social model of disability emerged and put a name to the approach they were taking (tenBroek, 1966, p. 842).

But other social structures also have a significant effect on equality for people with disabilities. These may be referred to as “background social structures.” They form a background against which other arrangements and practices operate, but their effects on the equality of disabled persons may be less apparent than those of staircases, inaccessible buses, and one-size-fits-all education.

Employment is an area in which background structures have a weighty impact on disabled persons. A study of several employment-related social arrangements and how they differ in the U.S. and Canada may provide insight about the prospects for equality for disabled persons in both countries. Drawing Canadian and American comparisons, this paper describes three such structures and discusses how their reform may be possible and could enhance equality for people with disabilities. Each social structure discussed here has a major legal dimension. This paper adopts an intermediate level of generality in its discussion, focusing neither on technical differences in interpretation of specific Canadian and U.S. disability discrimination statutes (Weber, 2010, p. 1171) nor on broad generalizations (Lipset, 1990, p. 2) about comparative Canadian and American culture.

## Background Social Structures Related to Employment and the Law

Consider three background structures concerning employment and its legal regulation for which the United States-Canadian comparison may be useful: (1) the legal doctrine of employment at-will as opposed to notice or severance pay in lieu of notice; (2) unionization or its absence; and (3) government-sponsored social insurance.

### At-Will Employment Versus Notice or Severance Payment in Lieu of Notice

The dominant legal structure for employment in the United States is employment at will, which applies generally to private employees, except those who are unionized and those in Montana (Arnow-Richman, 2010, p. 4). The employer may discharge the worker for any reason or for none at all, as long as the reason is not one forbidden by discrimination laws or other public policy (American Law Institute, 2009, § 2.01). Although Canadian law does not require that discharge be for cause, the law says that for any termination without cause, the employee must be provided either adequate notice or a salary payment as severance in lieu of notice (Bird & Charters, 2004, p. 205). The requirement of providing notice or severance creates a disincentive to discharge, in effect saying “you can fire the employee, but it will cost you.” Conversely, an incentive is created to provide accommodations or other means to make workers more successful and keep them employed. Moreover, in the United States a discharge without cause is sufficiently common to trigger no special scrutiny and thus provides a good shield for hidden discrimination (McGinley, 1996, p. 1462). The notice-or-severance policy makes it a rarer event in Canada. In fact, many Canadians incorrectly believe they cannot legally be discharged absent just cause (Bird & Charters, 2004, pp. 242-43).

However, the risk of a costs award that will include significant attorneys’ fees against a litigant who is unsuccessful (Knutsen, 2010) may deter Canadian workers from taking notice-severance claims to court, even when they have the law on their side. In addition, American litigiousness (Lipset, 1990, p. 100) may equalize the likelihood of American and Canadian challenges to discharge to some degree.

### Unionization or Its Absence

Unionization is much more prevalent in Canada than in the United States, especially in the public sector, where Canadian union density is 78%, in contrast to the American number of 36% (Finlayson, 2007). The Canadian legal framework for unions is widely viewed as more supportive than the American one (Titkemeyer, 2006). Canada regards collective bargaining as a fundamental right. The Canadian Supreme Court has applied the Canadian Charter of Rights and Freedoms to overturn legislation applicable to public sector bargaining that had suspended union agreements, restricted contract terms, and limited the scope of bargaining (*Health Servs. & Support Facilities Subsector Bargaining Ass’n v. B.C.*, 2007). In contrast, a leading American court decision upheld the federal government’s refusal to negotiate with a public workers’ union about a program of performance incentives, finding the subject non-negotiable under applicable law (*Nat’l Treasury Employees Union v. Fed. Labor Relations Auth.*, 1986).

Unionization helps workers who have disabilities. As Malhotra (2009, p. 103) has written, the presence of a union opens up arbitration as a way to enforce accommodation rights, and as Lynk (2008, p. 224-226) demonstrated, Canadian labor arbitration is more effective than are human rights tribunals or courts in enforcing disability accommodations and obtaining reinstatement for workers when appropriate. Taking a disability discrimination complaint to arbitration with union support is likely to be far less onerous for the employee than the widespread American practice of finding an attorney—which may be difficult given the poor record of success in litigation (Stein, Waterstone, & Wilkins, 2010, p. 1689)—and bringing a case to the federal courts.

It is true, as Malhotra (2003, p. 144-147) also indicates, that union-protected rights, such as seniority and the integrity of bargaining units, may conflict with accommodations such as transferring to other positions when an employee no longer can perform the functions of an existing job even with workplace modifications. Malhotra points out that under Canadian law, a tribunal may consider potential conflict with a union contract when evaluating an employer's refusal to provide accommodations (2003, p. 148). Moreover, the individual-focused interactive process of working out accommodations with the employer may conflict with collective bargaining practices. Nevertheless, both collective bargaining and seniority practices can be reconciled with accommodation rights if the employer and bargaining unit representative act in good faith (Bruyere, 1993, pp. 123-24).

On a more basic level, however, Canada's union-friendliness indicates a greater willingness to allow outsiders—both unions and courts—to intervene in the control of the workplace in Canada than in the United States. There is a strong management-prerogative ideology in the United States, and management prerogative is often relied on explicitly in judicial decisions in American discrimination cases. For example, in *Texas Department of Community Affairs v. Burdine* (1981), the United States Supreme Court said of Title VII of the Civil Rights Act of 1964, “The statute was not intended to diminish traditional management prerogatives” (p. 259). This American attitude of deference to the employer reinforces the reluctance of American judges to require employers to provide accommodations to disabled workers (O'Brien, 2001, pp. 3-4).

### Social Insurance Programs

In both countries social insurance benefits are available for individuals who meet a disability threshold. These benefits programs are exemplified by the Canadian Pension Plan, the Quebec Pension Plan (CPP/QPP), and U.S. Social Security Disability Insurance (SSDI). Both the Canadian and United States programs are relative newcomers to the social insurance structures in the two countries. The CPP/QPP disability program came into being in 1968 and started making payments in 1970 (Campolieti & Krashinsky, 2002, p. 419). SSDI came into being in 1956; a requirement that beneficiaries be 50 or older was repealed in 1960 (Weber, 2009, p. 583). The Canadian and American programs provide benefits to individuals who meet a standard of long-term and severe disability. Within limits, the level of benefits depends on the level of earnings before the onset of disability. However, the benefits are distributed in such a way that low earners receive a greater proportional amount in relation to prior income than higher earners.



Benefits under these programs are tied to having a record of work. Only chancier and more meager social safety net programs cover those who lack a long work history (Wiseman & Ycas, 2008). There is thus a premium on getting and keeping work, even apart from wages and whatever social connection and personal fulfillment a job may provide. The weakness of American government programs for impoverished people who lack a work history makes the problems of lack of social insurance coverage even more acutely felt below the 49th parallel than in Canada (Wiseman & Ycas, 2008, p. 61).

To the extent that work is unavailable for people who have disabilities in the United States and Canada, the result is severe income inequality uncushioned by public pensions. In the United States, Supplemental Security Income (SSI) may provide subsistence for people with disabling conditions, but its benefits are set at sub-poverty level: an amount about 70% of the federal poverty level. On the other hand, for workers who become disabled after an extensive employment history, social insurance payments offer a lifestyle that has some level of dignity (Weber, 2009, p. 603). The lack of work for people with disabilities in the United States and Canada results in severe income inequality uncushioned by public pensions. On the other hand, for workers who become disabled after an extensive employment history, social insurance payments offer a lifestyle that has some level of dignity (Weber, 2009, p. 603).

#### Reforming Background Social Structures

It is possible to undertake reforms to make these background social structures offer better opportunities for equality for disabled persons, and circumstances suggest that expending effort and resources on these reforms is worthwhile.

At-will employment is longstanding part of U.S. common law, one that has been challenged repeatedly with few successes (Feinman, 1976, pp. 118, 128-29). It is a bad sign for the challengers that the recent American Law Institute Restatement of Employment Law enshrines the principle (American Law Institute, 2009, §2.01). Permitting discharge only for cause would be a better rule than the Canadian rule of severance-in-lieu-of-notice for employees who are vulnerable to hidden discrimination, but notice-severance is surely better for disabled workers than at-will. Recent American legal scholarship supports the adoption of a legal requirement of advance notice before discharge (Arnow-Richman, 2010), and the WARN Act, requiring notice before mass layoffs, is an example of a limited U.S. reform along these lines (Worker Adjustment Retraining and Notification Act, 2006), so there may be a basis for optimism that the United States position might be nudged a little closer to Canada's through legislation or law reform litigation.

As for unionization, it would appear to be strongly in the interest of people with disabilities and allies to support unionization and laws that facilitate unionization, if only to weaken the ideology that management has an ironclad entitlement to make all of the decisions at the workplace, including those about accommodations. Moreover, as long as the union provides assistance, the arbitral forum is a good one for disabled workers. Malhotra (2009, pp. 101-102) has pointed out that non-unionized workers fare poorly in Canada in comparison to unionized workers with regard to accommodations. Perhaps the famous litigiousness of U.S. culture has some effect on promoting the disability accommodation rights of individual workers who lack

the support of a union. But on the whole it would seem in the interests of disabled people and their allies in both Canada and the United States to advocate for greater union power. At the same time, efforts to facilitate individual disability discrimination litigation by nonunionized Canadian workers may be in order.

On balance, social insurance programs benefit people with disabilities, so measures to strengthen them would appear desirable. Social insurance is a work incentive, and part of the overall rewards that come from work (Berkowitz, 2005, p. 23). It not only protects against the obvious economic risks that come with illness, accident, and age, but also provides some financial protection against the risk of disability discrimination. If after a person is disabled, no one will hire the individual even when he or she could work with accommodations, disability insurance furnishes a means of survival, typically at levels a good deal higher than the subsistence that may be available under poverty programs (Weber, 2009, p. 591).

Social insurance benefits are both generous compared to other forms of government support and relatively unlikely to be cut back in hard times because of the sense of entitlement created by funding through a dedicated payroll tax (Berkowitz, 2005, p. 23). Social insurance has been crucial in lifting the elderly out of poverty in the United States and Canada (Wiseman & Ycas, 2008). Nevertheless, social insurance alone is inadequate. Many individuals with disabilities lack the work history needed for social insurance eligibility (Erkulwater, 2006, p. 82) and continue to face poor or no employment options under current accommodation practices (Stein & Stein, 2007, p. 1210-1211). Public welfare programs will have to meet their needs (Erkulwater, 2006, p. 242). Proposals to bolster public welfare programs may meet resistance in the current political climate in North America, but people with disabilities and their allies should make the case for maintenance and expansion of social insurance.

### Conclusion

Background structures such as the nature of the employment contract, unionization, and social insurance arrangements, exert influence on the equal participation of people with disabilities in society. Reforms of these structures to promote equality appear both feasible and desirable.

**Mark C. Weber**, Vincent dePaul Professor of Law, DePaul University, is the author of *Disability Harassment* (NYU Press 2007) and *Understanding Disability Law* (Lexis-Nexis 2007). Correspondence should be addressed to Mark C. Weber, DePaul University, 25 E. Jackson, Chicago, IL 60604. Contact: [mweber@depaul.edu](mailto:mweber@depaul.edu).

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Disability, Able-Bodiedness, and the Biopolitical Imagination  
 Thomas Jordan, PhD.  
 Binghamton University

**Abstract:** Following the work of Hannah Arendt, Michel Foucault, and Giorgio Agamben, this article offers a theoretical analysis of the relationship between modern forms of biopolitics and discourses of disability and able-bodiedness in the context of globalization.

**Key Words:** Empire, Globalization, Biopolitics

While recent scholarship emerging out of the field of disability studies has sought to globalize the study of disability, this article addresses a series of conceptual gaps in current theorizations about disability, globalization, and practices of empire.<sup>1</sup> A number of leading scholars in the field of disability studies have pointed out the analytical limits of applying a Western model of disability oppression to alternative contexts, but few have articulated the complex relationship between discourses of disability and able-bodiedness and contemporary forms of biopolitics.<sup>2</sup> By placing the work of Hannah Arendt (1958), Michel Foucault (1979), and Giorgio Agamben (1995) in conversation with disability studies scholarship, this article examines the process by which forms of citizenship become invested in and defined through the bodies of citizens. To globalize the study of disability, the field must first articulate the varied ways that conceptions of disability and able-bodiedness function discursively in the control, maintenance, and organization of national populations.

Adapting the work of Jasbir Puar (2007) in *Terrorist Assemblages: Homonationalism in Queer Times*, Robert McRuer (2010), David Mitchell and Sharon Snyder (2010), and Kristen Aherns (2010) have offered a significant element to the global analysis of disability by linking it directly to the biopolitical ends of empire (and its multiple valences, both national and global). According to McRuer (2010), Puar is able to demonstrate the varied ways that the “biopolitics of Empire now target certain lesbian and gay, and even ‘queer,’ subjects for life while simultaneously queering ‘terrorist corporealities’ and targeting them for death” (p. 169).

Puar (2007) troubles the heterosexual/homosexual binary by showing how the state produces normative gay and lesbian identities in order to police more strictly alternative forms of queerness, consolidating ever-narrowing forms of white racial privilege in the process. Mitchell and Snyder (2010) coin the term “able-nationalism” in order to extend Puar’s analysis of gay and lesbian identities to disabled identities; they name the process by which some disabled subjects (“super-crips”) are nominated as exemplars of national values of progress in order to bolster an ideology of neoliberal inclusiveness, while other disabled subjects are targeted as waste within the global economy.<sup>3</sup>

For Mitchell and Snyder (2010), “recent able-nationalisms” have managed to situate “some mutant bodies as effectively and normatively disabled,” allowing disabled people to “perform their representational work as a symbol of expansive neo-liberal inclusion efforts” (p. 116). According to their analysis, the task of globalizing disability studies must also be the task of recognizing how some disabled subjects are made hyper-visible in order to render other disabled subjects invisible and beyond the bounds of neoliberal rationality.

The theoretical move initiated by these scholars begs a deeper consideration of the ways that the discursive logic of disability can often exceed the material state of the body and produce its own reality effects. In Lennard Davis's (1995) foundational text, *Enforcing Normalcy: Disability, Deafness, and the Body*, he argues:

“The problem, of course, is that the manner in which this society defines disability in fact creates the category. Able-bodied (or temporarily able-bodied) people safely wall off the severely disabled so that they cannot be seen as part of a continuum of physical differences, just as white culture isolates blackness as a skin color so as not to account for degrees of melanin production. How many people with hearing aids consider themselves deaf; how many people with knee braces consider themselves impaired?” (p. 7)

In light of Mitchell and Snyder's (2010) analysis of the “able-disabled,” and, in addition, its inverse, the disabled able-bodied, it is not enough for disability studies to simply deconstruct the able-bodied/disabled binary in order to recognize disability along “a continuum of physical differences” that defines human variation in general. Instead, it is incumbent upon the field to consider more fully how the ideology of neoliberal inclusiveness and modern forms of biopolitics actually profit from the instability of previously fixed categories of identity and difference. As the recent work of McRuer (2006; 2010) and Mitchell and Snyder (2010) suggests, processes of globalization blur the lines between the able-bodied and disabled in some contexts while reconstituting them in both stricter and more subtle ways in others.

To advance McRuer's (2010) recent effort to think the “uneven biopolitical incorporation” of “disabled subjects who in certain times and places are made representative and ‘targeted for life’ even as others are disabled in different ways, or crippled, or targeted for death” (p. 171), the field of disability studies must first develop a nuanced theoretical approach to the relationship between disability and the biopolitical imagination that has characterized the development of Western civilization and its liberal political tradition. In writing about contemporary forms of biopolitics, Giorgio Agamben (1995) argues that “only a politics that will have learned to take the fundamental biopolitical fracture of the West into account will be able...to put an end to the civil war that divides the peoples and the cities of the earth” (p. 180). Following McRuer, this article argues that the disabled/able-bodied binary informs the process by which the politics of life transforms into the politics of death, allowing for disability to act as the symbolic justification for the violence perpetuated by modern forms of empire.

### Discourses of Disability

For the purposes of my argument, the phrase “discourse of disability” refers to a series of statements and writings that accrue over time and imbue a physical or mental difference with social meaning and value. Discourses are not simply representations, but representations that have achieved a general sense of approbation, to the point where they appear to articulate the world as it *really* is. Focusing on discourses of disability rather than disabilities themselves does not aim to deny the material reality of physical and mental difference, but only to suggest that physical and mental differences do not carry an innate value. In other words, disability only becomes a problem, a limit, or a disadvantage within a specific social context. Discourses of

able-bodiedness operate in a similar fashion; one can only identify as an able-bodied subject within the institutional frameworks and through the cultural discourses that define able-bodiedness and describe how the able-bodied should appear.

Thinking in terms of discourses of disability helps open up critical space to theorize the gap between representations of disabilities and their physical manifestations. As so many disabled activists and scholars have noted, the experience of a disability is often far more influenced by cultural attitudes associated with disability than any physical consequences resulting from impairment. The gap between the personal experience of a disability and its larger cultural evaluation becomes even more complex when theorized in relationship to other categories of difference, such as race, class, gender, and sexuality. As Douglas Baynton (2001) explains, “disability has functioned historically to justify inequality for disabled people themselves, but it has also done so for women and minority groups” (p. 33). When the language of disability is used to describe an entire population of non-disabled people in order to justify their exclusion from full political membership in a society, discourses of disability lose their connection to the physical body entirely. Far from articulating the complexity of an embodied state, such discourses rely on the negative cultural associations of disability to stigmatize diverse groups of people and deny them basic human rights. The fact that so many Western nations have relied upon discourses of disability to produce exceptions to their laws only shows how deeply related the concepts of able-bodiedness and citizenship are in the West.<sup>4</sup>

#### Disability Oppression in the West

If discourses of disability have often been deployed historically to justify the social marginalization of all types of minority groups in the West, this tendency presents a conceptual problem for the field of disability studies. It asks scholars to consider why disability, in particular, is considered such a convenient and natural mark of social inferiority. The danger, of course, is to read disability oppression as an evolutionary phenomenon, the inevitable result of the human desire for reproductive fitness. Once disability oppression is linked to human biology, it is divested of its political implications.

In contrast, when discourses of disability are examined in relationship to the biopolitical aims of the state, even the earliest forms of biopolitics help reveal the tacit political connection between disability and social oppression and exclusion. When Aristotle writes that “[human beings are] born with regard to life, but existing essentially with regard to the good life,” he articulates the ancient Greek distinction between natural life and political life (Agamben, 1995, p. 2). Hannah Arendt (1958) elaborates on this division in *The Human Condition* when she distinguishes between labor, work, and action, where labor, or the *animal laborans*, “corresponds to the biological process of the human body, whose spontaneous growth, metabolism, and eventual decay are bound to the vital necessities produced and fed into the life process by labor. The human condition of labor is life itself” (p. 7). According to Arendt, the ancient Greeks relegated labor to the private sphere of the home while privileging the political and public life of action. For Agamben (1995), this distinction corresponds to the privileging of *bios*—“the form or way of living proper to an individual or group”—over *zoe*—“the simple fact of living common to all living beings” (p. I).

In the classical world, the physical needs of the body were excluded from the political realm. As Arendt (1958) explains, “what men [*sic*] share with all other forms of animal life was not considered to be human” (p. 84). In this way, citizenship referred to a process of disembodiment, where citizens were released from the strictures of the bodily labor associated with the home and free to concentrate on the higher intellectual aims of the polis. But in practice, disembodiment cannot be distinguished from able-bodiedness, since the minimum requirement for citizenship was really the ability to account for your basic needs autonomously in the private space of the home. The inability to account for the basic needs of the human body discretely and in private became a mark of subhuman status.

Under this schema, disability was often interpreted as a visible sign of the body’s physical needs, allowing disability to become associated with *zoe* and able-bodiedness *bios*. The ancient Greek “conviction[s] that life without health [was] not worth living...and that suicide [was] a noble gesture to escape a life that has become burdensome” exemplify the way disabled subjects became devalued within ancient Greek society (Arendt, 1958, p. 315). For the ancient Greeks, a person burdened with ill health or severe impairment was incapable of experiencing an “autonomous and authentically human way of life” (Arendt, 1958, p. 13). Instead, the life of the free citizen acting in the sphere of the polis constituted the highest form of man’s being in the world, or Aristotle’s “good life.”

The distinction between *bios* and *zoe*, or the good life and bare life, helps to explain the process by which disability gradually comes to mark the exception to the contemporary political order. By defining disability against citizenship, the ancient Greeks would set the stage for later discourses of disability deployed to deny diverse groups of people their citizenship rights in the West. The ancient Greeks’ privileging of *bios* over *zoe* reveals disability oppression to be a distinctly political process rather than a long evolutionary progression. The ancient Greeks elevated some aspects of human experience over others, privileging the human potential for intellect over the animal substratum that also made up part of human nature. In the process, disability came to mark a liminal zone separating human from animal, where disability represented something human that was refused acknowledgement as such. Only a perspective that understands the long history of disability oppression in the West as a distinctly political phenomenon will be able to recognize how discourses of disability and able-bodiedness have been translated by modern forms of biopolitics.

### Rethinking Foucault: Disability Studies and Biopolitics

If disability has historically marked the exception to the Western political order, then this provides a slight nuance to the interpretation that many disability studies scholars have offered for the relevance of biopolitics to the study of disability, particularly in relation to the work of Michel Foucault. While Foucault is often cited as an important predecessor to the still growing field of disability studies, too often disability studies scholars have sought to link Foucault’s docile body, produced by modern technologies of discipline, to the disabled body.<sup>5</sup> Tobin Siebers’s (2008) discussion of Foucault in *Disability Theory* provides a primary example of this critical tendency. For Siebers (2008), Foucault’s docile body—“the body invented by the modern age”—is really just the disabled body in disguise (p. 58). Siebers dismisses Foucault’s poststructural account of the body as part of a larger argument that takes aim at social



constructionist accounts of physical difference, suggesting that this type of analysis inevitably seeks to return to a healthier, fitter, and more natural version of the body that processes of signification have either blurred or substantially delimited.

Siebers's argument rests largely on a series of passages drawn from Foucault's (1979) *Discipline and Punish* two of which are reprinted below:

“The soldier was someone who could be recognized from afar; he bore certain signs: the natural signs of his strength and his courage, the marks, too, of his pride; his body was the blazon of his strength and valour.

By the later eighteenth century the soldier has become something that can be made; out of a formless clay, an inapt body, the machine required can be constructed; posture is gradually corrected, a calculated constraint runs slowly through each part of the body, mastering it, making it pliable” (p. 57-58)

The contrast presented by the depictions of the seventeenth and eighteenth century soldier provides compelling evidence for Siebers's conclusion that Foucault's work romanticizes the health and fitness of a previous age. As a representative of this earlier type of fitness, the first soldier stands erect, the natural emblem of an internal strength of mind and body that marks his calling. The second soldier, on the other hand, appears to lack this strong sense of physicality; while his body suggests a latent potential, it must be trained, sculpted, and adapted in order for that potential to be maximized. But Foucault (1979) is less concerned with the comparative physical merits of either soldier than the historical question of their verifiability as soldiers (p. 135-136). In other words, Foucault is interested in what makes a soldier a soldier, and how that truth can be measured. In the first case, the soldier's identity is verifiable through his physical attributes, traits gifted at birth, natural affinities for running, jumping, marching, and fighting.

For the second soldier, physical attributes are merely the raw material for a much more complex process of verification. This involves a training regimen and a series of drills and learned behaviors, but also an accounting process, a series of measurements, and a careful inventory of skills to ensure the effectiveness of that training. The problem with Siebers's critique is the suggestion that, despite Foucault's many claims to the contrary, his historical arguments are always implicitly evaluative, that he is nostalgic for a vision of the past.

In Siebers's (2008) argument, the docile body is the object of a profound form of repression, a reading that makes sense if “all of [Foucault's] major writings are dedicated to tracking their [‘madness,’ ‘criminality,’ and ‘sexuality’] involvement with social repression and exclusion” (p. 57). But perhaps the most innovative aspect of Foucault's work is the theoretical move he makes away from the traditional juridico-institutional approach to the problem of power in order to imagine a form of power that is not simply repressive but also productive. The concept of biopower allows Foucault to trace the many ways that power invests subjects at the level of the body, taking hold of all aspects of the life process. For Foucault, power is never simply a top-down affair; instead, it refers to a profoundly relational phenomenon. Even a cursory look at Foucault's work reveals that “repression” and “exclusion” do not occupy privileged spaces in his lexicon.

The fundamental difference between the two soldiers described above is that the second is the object of this new form of biopower. According to Foucault, the charge of biopower is to take hold of human life in all its aspects, “right down to the depths of society” (Foucault, 1979, p. 27). This type of power is invested in processes of economy and efficiency but also normalization; subjects begin to internalize the norms of the population to the point where they police themselves, suturing their identities around the larger biopolitical aims of the state.

Foucault chooses to study the prison and the mental asylum because they are privileged sites from which to view the operation of power on the body of the subject, and it is significant to remember that the very idea of panopticism does not simply refer to Bentham’s ideal prison but rather the prison as the perfect functioning of a mode of discipline that has invested the population at large. If Foucault (1979) looks to sites of “exclusion” for his analysis, it is in an effort to shed light on the contemporary norm, and this is precisely what he means when he argues that he is writing a “history of the present” (p.31).

Siebers (2008) mistakenly associates the docile body with disability by over-investing in the spatial mechanics of Foucault’s analysis. The contrast presented in the two soldiers’ bodies does not distinguish between the able body and the disabled body, but rather, between types of able-bodiedness. The docile body is equivalent to the modern conception of the able body, where able-bodiedness names biopower’s functional end. This explains the shift in emphasis in the context of the prison and asylum from punishment and containment to rehabilitation—the object of biopower is the reintroduction of the normalized subject into society.

But the close relationship between biopower and able-bodiedness also suggests that able-bodiedness refers not simply to a privileged form of identity but more immediately to a regulatory discourse. As a regulatory discourse, able-bodiedness does not name a form of repression, but a form of subjectification and control. As discourses of able-bodiedness invest the population around a series of measurable and increasingly differentiable norms, individual subjects begin to model their behavior according to normative expectations.

What Foucault’s work seems to intuit but never makes explicit is that the discourse of able-bodiedness, far from trying to eliminate the disabled body, requires it as a permanent threat and an imminent possibility for its very operation. In other words, disability and able-bodiedness name two sides of the same biopolitical coin, but this is a point that requires Agamben’s theory of sovereign power and bare life for further analysis.

### Disability and Modernity: A New Biopolitical Paradigm

Both Foucault and Arendt characterize modernity in precisely the same way, though they arrive at the conclusion separately: the threshold of modernity is constituted by the politicization of the unqualified body, simple human life. For Arendt (1958), scientific modernity names the process by which labor, the *animal laborans*, rises to central importance within the sphere of politics.

Foucault’s (1990) analysis concurs: “For millennia man [*sic*] remained what he [*sic*] was for Aristotle: a living animal with the additional capacity for political existence; modern man

[sic] is an animal whose politics calls his [sic] existence as a living being into question” (p. 143). Once the *animal laborans* (or Agamben’s *zoe*) is linked to the disabled body, disability becomes stigmatized in the West as a symbol of the strictly biological needs of the human body.

The conclusion might follow that if the project of modern biopolitics is invested primarily in the biological processes of its subjects, disability would find a measure of inclusion in this new paradigm of rule. On the surface, this appears to be the case, particularly with the deinstitutionalization movement and legislation like the Americans with Disabilities Act (1990) that seeks to guarantee the civil rights of disabled populations.

Likewise, Davis (2002) has demonstrated the ways that disability finds inclusion as a market identity within the newly globalized economy. At the same time, there are dangers associated with this line of thought, which corresponds to a type of progress narrative associated with disability liberation. Even as the old walls of the institution begin to crumble, the group home, the nursing home, the special education classroom, and the government-funded facility continue to mark a point of separation between the able-bodied and the disabled.

From a global perspective, the inclusion of disabled subjects is also severely limited. In Achilles Mbembe’s (2003) essay “Necropolitics,” he offers the concept of a “death-world” to describe “new and unique forms of social existence in which vast populations are subjected to conditions of life conferring upon them the status of *living dead*” (p. 40).<sup>6</sup> Given that there are more than a half billion disabled people in the world today and that 80 percent live in developing countries, the intersections between impaired bodies and the creation of death-worlds are multifarious (Davidson, 2008, p. 117).

In such spaces, the visibly fragmented body marks a liminal position between life and death. While the social conditions conferred upon Mbembe’s (2003) “living dead” produce disproportionate numbers of disabled people, their disabilities perform the symbolic work of justifying those unequal living conditions.<sup>7</sup> The “death-world,” then, relies on a form of circular logic that inverts its temporal manifestation, where acts of violence are justified by the disabilities they produce.

Neither Foucault nor Arendt can answer the competing and contradictory claims represented by the simultaneous inclusion and exclusion of the disabled body that characterizes modernity and the current age of global capital. For Agamben (1995), the primary limitation of Foucault’s (and by extension, Arendt’s) theoretical analysis is their inability to define the precise relationship between the law and specific forms of biopower (p.6). Agamben (1995) asks, “Where is the zone of indistinction (or, at least, the point of intersection) at which techniques of individualization and totalizing procedures converge?” (p. 6). In other words, at what point do sovereign acts of violence and modern technologies of discipline intersect and inform one another?

Agamben (1995) answers this question with the concept of bare life, or the life of *homo sacer*, “who may be killed and yet not sacrificed” (p.8).

The Disabled/Able-Bodied Binary and the Sovereign Decision over Life and Death

Bare life should be understood as both the foundation upon which the Western juridical order is erected and the object of biopower par excellence. According to Agamben (1995), sovereignty is constituted by the sovereign's sole power to proclaim the state of exception, and the space of the exception is characterized by the production of bare life.<sup>8</sup> In other words, the "production of bare life is the originary activity of sovereignty" (p. 83).

Agamben continues, "the sovereign sphere is the sphere in which it is permitted to kill without committing homicide and without celebrating a sacrifice, and sacred life—that is, life that may be killed but not sacrificed—is the life that has been captured in this sphere" (p. 83). For Agamben, the originary activity of sovereignty is the production of excepted populations, or groups of people who are stripped of their political rights and can be murdered without consequence.

Where Agamben parts ways from Foucault and Arendt is in the assumption that the inclusion of simple life—*zoe* or the *animal laborans*—in the political realm distinguishes the modern age from the classical world of the ancient Greeks. Instead, Agamben argues that the concept of *zoe* has always been included within the political world of the West by measure of its very exclusion. As he explains, "bare life remains included in politics in the form of the exception, that is, something that is included solely through an exclusion" (p. 11).

For the ancient Greeks, *zoe* was relegated to the private sphere of the home while the qualified life of politics occupied the sphere of the polis. But in the effort to define the "good life" as the absence of bare life, bare life became fundamental to the very concept of Western politics—it was the included exclusion upon which the concept of political sovereignty became founded. The modern age of biopolitics does not, then, represent the first time that bare life has been included within the realm of politics in the West. Instead, as the state of exception becomes the rule,<sup>9</sup> or as the state of exception becomes the state's working paradigm of government, the distinction between *bios* and *zoe* is no longer tenable: "exclusion and inclusion, outside and inside, bios and zoe, right and fact, enter into a zone of irreducible indistinction" (Agamben, 1995, p. 9).

What Foucault and Arendt recognized as a new form of biopolitics was actually a qualitative shift in the politics of life, where the separation of bare life and political life could no longer be easily distinguished. According to the logic of my argument, as bare life and political life enter into a zone of indistinction, so too must the concepts of disability and able-bodiedness.

Just as Foucault (1979) conceived of his work as "a history of the present," Agamben's conception of bare life becomes most significant in relation to the contemporary paradigm of rule. As Slavoj Žižek (2010) explains:

"The distinction between those who are included in the legal order and *homo sacer* is not simply horizontal, a distinction between two groups of people, but is increasingly also a "vertical" distinction between two (superimposed) ways in which *the same* people can be treated" (p. 25)

According to Žižek (2010), once exclusion and inclusion enter into “a zone irreducible indistinction,” the lines separating citizen from non-citizen also become ambiguous (Agamben, 1995, p. 9). For this reason, Žižek (2010) argues that “the implication of [Agamben’s] analysis of *homo sacer* is not that we should fight for the inclusion of the excluded, but that *homo sacer* is the ‘truth’ of all of us” (p. 125).

To fight only for the inclusion of the excluded is to misunderstand the precarious position in which all human beings find themselves today, where anyone can become excluded from the rights of political membership at any time. At a basic level, “we are *all* ‘excluded’ in the sense that our most elementary, ‘zero’ position is that of being an object of biopolitics,” so that the rights of all citizens are always secondary to the biopolitical aims of the state (Žižek, 2010, p. 125).

Together, able-bodiedness and disability represent dueling yet complicit sides of the “zero” position to which Žižek (2010) speaks. Globalization presents not just a zone of indistinction but a zone of fluidity through which the disabled become able-bodied and the able-bodied become disabled. Only this notion of a zone of indistinction makes sense of the fact that in the very name of the health of the body, modern biopolitics proliferates new forms of impairment and disease with ever finer gradations of symptoms, or the fact that so many “cures” produce their own ailments. And only this notion of a zone of fluidity can help to elucidate the point at which the disabled body becomes the site of the decision between value and nonvalue under which the politics of life transforms into the politics of death.<sup>10</sup>

Globalization is not simply opposed to the nation-state—in fact, the forces of globalization often provide new spaces through which the state of exception can operate. The lesson that thinking of bare life in terms of disability provides is not that anyone can become disabled at any time—this is a lesson that the field of disability studies has long been aware of. Instead, the lesson is that *anyone* can be produced as a disabled subject at any time as the exception becomes the rule.

Agamben illuminates the double register of bare life in order to bring into visibility the process by which the state of exception passes judgment on all our lives, but understanding bare life in relationship to disability adds an important affective register to his analysis. If Agamben seeks to articulate the biopolitical schism at which point biopolitics becomes thanatopolitics, the discursive distinction between the disabled body and the able body helps explain how subjects become invested in that schism without recognizing their precarious position within it.

At the point of decision where the sovereign passes judgment on the bodies of the population, the disabled/able-bodied binary produces the evaluative logic which separates the body that must die from the body that is targeted for life. This is the point at which the able-bodied subject can recognize the disabled subject only as an enemy—the disabled body becomes the static object of fear or pity while the able body masquerades as the precondition for the pursuit of happiness. If the end of biopolitics is the production of the able-bodied subject, then the end of thanatopolitics is the elimination of the disabled subject. The decision between life and death not only unites the able-bodied and disabled through their mutual exclusivity, it suggests that the knowledge of one cannot be produced outside of the knowledge of the other.

## Hurricane Katrina and Memorial Medical Center

The events that took place at Memorial Medical Center in New Orleans following Hurricane Katrina provide a material example of the largely theoretical analysis above. When doctors and nurses at Memorial decided to inject at least seventeen patients with lethal doses of drugs following Hurricane Katrina, they reduced their patients to the status of Agamben's bare life, or *homo sacer*, "who may be killed and yet not sacrificed" (p. 8).

As relief efforts were slow to arrive and the hospital lost power and running water, the medical professionals at Memorial decided to appraise their patient's lives. The patients were divided into three groups: group 1 consisted of patients who could sit up and walk and they would be evacuated first; group 2 included sicker patients that required physical assistance in order to move; group 3 patients required significant assistance and were scheduled last for evacuation (Fink, 2009, p. 7).<sup>11</sup>

The patients at Memorial were separated according to the severity of their impairments, where the lives of the healthiest patients were prioritized above the lives of their sicker counterparts. In choosing to evacuate the healthiest patients first, the doctors at Memorial acted upon the tacit assumption that the able-bodied have more to live for than the disabled.

The events at Memorial provide a powerful example of the theoretical claim that in the modern age, the disabled body becomes the site of the decision over life and death at which point biopolitics transforms into thanatopolitics. Before Katrina hit, LifeCare Hospitals of New Orleans leased Memorial's seventh floor and catered to critically ill or injured patients (Fink, 2009, p. 4). LifeCare, as Sheri Fink (2009) points out, was not a hospice—they specialized in rehabilitating "patients on ventilators until they could breathe on their own" (p. 5). Following the Hurricane, almost a third of LifeCare's patients were given lethal combinations of drugs to ease their pain and hasten their deaths. In a 72-hour period, LifeCare's whole *raison d'être* experienced a 180 degree shift—no longer concerned with the prolongation of life, the hospital's staff turned their attention to the administration of death.

If the floodwaters of Katrina forced the doctors and nurses at Memorial into a precarious situation, the specific choices they made to handle that situation relied upon longstanding cultural assumptions for their justification. When Memorial's staff categorized all patients with "Do Not Resuscitate" orders as level "3's" for evacuation, their decision had little to do with the extreme conditions produced by the disaster. In an interview with Fink, Bill Armington, a neuroradiologist at Memorial, explained, "patients who [did] not wish their lives to be prolonged by extraordinary measures wouldn't want to be saved at the expense of others" (Fink, 2009, p. 4).

Of course, a DNR order makes no such claim, only stating that a patient does not wish to be revived if his or her breathing or heartbeat stops. In deciding to euthanize many of their patients with DNR orders (and some without), the staff at Memorial chose not to consult them. This omission was particularly glaring in cases where patients were well aware of their surroundings and waiting anxiously for their evacuation.

The actions of the doctors and nurses at Memorial exemplify Agamben's (1995) conclusion that "the sovereign decision on bare life comes to be displaced from strictly political motivations and areas to a more ambiguous terrain in which the physician and the sovereign seem to exchange roles" (p. 143). But the "terrain" to which Agamben speaks is far more ambiguous still. When stories of the deaths at Memorial reached the press, an overwhelming majority of the public agreed with the decisions of Memorial's staff. While the Orleans Parish assistant district attorney admitted that he and the district attorney "weren't gung-ho" about prosecuting the doctors and nurses at Memorial, the public outcry against prosecution certainly impacted the New Orleans grand jury decision not to indict Anna Pou, a lead physician at Memorial, and two of her nurses, on second degree murder charges (Fink, 2009, p. 24). Through community rallies, letters to the district attorney, and talk radio calls, the citizens of New Orleans affirmed the sovereign acts of Memorial's doctors and nurses—in the court of the public, they were viewed as heroes rather than murderers.

The irony of this response is that the decision to euthanize patients reproduced the logic of exclusion that made New Orleans so vulnerable to Katrina in the first place. As early as 2004, the *Philadelphia Inquirer* had run a story about the Bush administration's failure to reinforce the levees in New Orleans, explaining that the money had been "moved in the president's budget to handle homeland security and the war in Iraq."<sup>12</sup> The US Government decided to take funds away from the support infrastructure of a largely poor, black, and disproportionately disabled population of US citizens.<sup>13</sup> But if the Bush administration tacitly identified what type of person deserves protection in the US, their actions were mirrored by the doctors and nurses at Memorial who decided what type of person deserves to be saved during an emergency.

The public response to the events at Memorial suggests the degree to which the sovereign decision on bare life becomes invested in the population itself, where the citizen begins to assume the role of the sovereign. In other words, the citizen is asked to render the decision on bare life even as he or she occupies the "zero-level" position that it names. The fantasy induced by processes of globalization and recent able-nationalisms occludes the fact that able-bodiedness and disability structure the biopolitical imaginary, allowing able-bodied citizens to imagine themselves as altogether different from the disabled at precisely the moment where a decision must be made.

Only from this position of absolute difference can the able-bodied pass sentence on the disabled without recognizing their own fate on the faces of those they condemn. It might at first seem like an exaggeration to link the institution, the group home, and the nursing home to Agamben's discussion of the camp, but they all represent permanent spatial locations where the fact of "whether or not atrocities are committed depends not on law but on the civility and ethical sense" of care workers (Agamben, 1995, p. 174).

Where else is the citizen's sovereignty over the question of bare life more commonly recognized than in the child's reluctant decision to overturn their parents' wishes and remove them to the nursing home, a place where care workers are underpaid and abuse goes largely unchecked? The spatial locations of separation that constitute many disabled peoples' lives are not unrelated to the emergence of the new spaces of exception presented by refugee camps, detention centers, disaster areas, and terrorist holding cells. In fact, these permanent spaces of

exclusion are ideological anchor points by which the exception gradually becomes accepted as the rule.

### Conclusion

The disabled/able-bodied binary has become more mobile in the contemporary moment, where the state, along with its capitalist infrastructure, draws on disability rights discourses and inclusion efforts in order to furnish an image of multicultural benevolence and render invisible the processes by which it disables other populations in alternative contexts. If discourses of disability have gradually come to legitimate the state of exception, the logic of sovereignty has begun to inform the decisions of the population at large, particularly at times of personal or communal crisis.

Where Agamben's analysis falls short is in its inability to adequately theorize the social stratifications that make some groups of people far more vulnerable to sovereign practices of violence than others. The process by which the able-bodied become disabled discursively is often inflected by other categories of difference, including race, gender, sexuality, and particularly, class. Agamben (1995) writes that:

“Until a completely new politics—that is, a politics no longer founded on the *exceptio* of bare life—is at hand, every theory and every praxis will remain imprisoned and immobile, and the “beautiful day” of life will be given citizenship only either through blood and death or in the perfect senselessness to which the society of the spectacle condemns it” (p. 11)

Recognizing able-bodiedness and disability as twin sides of the biopolitical imagination can contribute to the new politics to which Agamben gestures by denaturalizing the logic of ability that informs modern processes of exclusion and extermination. Such a project can help recast questions of human agency and ethics away from the discourse of human rights and its close alliance with neoliberal ideology to consider much more deeply our shared vulnerabilities as a human community.

**Thomas Jordan, PhD.** is currently an instructor of English at Binghamton University. In Fall of 2013, he will be starting as an assistant professor of English at Upper Iowa University. Thomas Jordan received his PhD in English from Binghamton University in May of 2011. His dissertation project, entitled *The Empire of Ability: American Exceptionalism and the Specter of Disability*, provides a cultural and political analysis of the US empire through the lens of disability studies. Dr. Jordan can be reached at [tjordan1@binghamton.edu](mailto:tjordan1@binghamton.edu).

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#### Endnotes

<sup>1</sup>In their introduction to *The Global Transformations Reader*, David Held and Anthony McGrew (2003) provide a clear and concise definition of globalization: “Simply put, globalization denotes the expanding scale, growing magnitude, speeding up and deepening impact of interregional flows and patterns of social interaction. It refers to a shift or transformation in the scale of human social organization that links distant communities and expands the reach of power relations across the world’s major regions and continents” (p. 4). By defining globalization around a series of descriptive terms that primarily denote a quantitative change in scale, Held and McGrew suggest that while interregional flows and patterns of social interaction are not new, they have never been so dominant in the structuring of a truly global economy.

<sup>2</sup>See recent scholarship by Ato Quayson (2007), Lennard Davis (2002), Michael Davidson (2008), Robert McRuer (2006), David Mitchell and Sharon Snyder (2010), Anita Ghai (2002), and Nirmala Erevelles (2010), among others, which has sought to extend the parameters of disability studies analysis beyond its traditionally Euro-American context.

<sup>3</sup>Neoliberalism is not meant as a synonym for globalization. As McRuer (2006) explains, “Above all, through the appropriation and containment of the unrestricted flow of ideas, freedoms, and energies unleashed by the new social movements, neoliberalism favors and implements the unrestricted flow of corporate capital. International financial institutions (IFIs) and neoliberal states thus work toward the privatization of public services, the deregulation of trade barriers and other restrictions on investment and development, and the downsizing or elimination (or, more insidiously, the transformation into target markets) of vibrant public and democratic cultures that

might constrain or limit the interests of global capital. These cultural shifts have inaugurated an era that, paradoxically, is characterized by more global inequality and raw exploitation and less rigidity in terms of how oppression is reproduced (and extended)” (p. 2-3). For the purposes of this article, neoliberalism names the dominant ideology underlying current processes of globalization

<sup>4</sup>Examples of such practices abound throughout American and European history, particularly in relation to projects of colonialism. Perhaps the most heinous example of disability being used to signify various forms of abjection occurred during the Nazi final solution. As Zygmunt Bauman (1989) explains, “It is difficult, perhaps impossible, to arrive at the idea of extermination of a whole people without race imagery; that is, without a vision of endemic and fatal defect which is in principle incurable and, in addition, is capable of self-propagation unless checked” (p. 73). Bauman demonstrates that the type of racism responsible for the holocaust necessarily rested on the logic of disability (a “fatal” and “incurable” “defect”) for its explanatory power.

<sup>5</sup>See Tremain (2005) for a diverse range of Foucauldian interpretations of disability and able-bodiedness. <sup>6</sup>Necropolitics, and Agamben’s thanatopolitics, refer to the politics of death. Both terms suggest the sovereign’s right to rule over the life and death of the population. When Agamben (1995) speaks of the “fundamental biopolitical fracture of the West,” he names the point at which the politics of life transforms into the politics of death (p. 180).

<sup>7</sup>Mbembe (2003) writes, “In other cases, in which physical amputation replaces immediate death, cutting off limbs opens the way to the deployment of techniques of incision, ablation, and excision that also have bones as their target. The traces of this demiurgic surgery persist for a long time, in the form of human shapes that are alive, to be sure, but whose bodily integrity has been replaced by pieces, fragments, folds, even immense wounds that are difficult to close. Their function is to keep before the eyes of the victim—and of the people around him or her—the morbid spectacle of severing (p. 35). We can add to this Davidson’s (2008) point that “There are more than one-hundred-ten million land mines in sixty-four countries. There are one and a half mines per person in Angola, where one-hundred-twenty people per month become amputees. There are twelve million land mines in Afghanistan, one for every two people. It seems hardly necessary to add that land mines are created not to kill but to disable, thereby maximizing the impact of bodily damage on the extended family and community” (p. 117).

<sup>8</sup>The state of exception refers to the sovereign’s right to suspend the law in a time of crisis.

<sup>9</sup>The Bush homeland security state offers a paradigmatic example of Agamben’s state of exception. Measures like the Patriot Act suspended the individual rights of citizens indefinitely in the interests of national security. According to Agamben, as the state of exception becomes a working paradigm of government, the rights of all citizens become vulnerable.

<sup>10</sup>The theoretical concept of a “zone of fluidity” recalls my earlier discussion of the way discourses of disability are often deployed to justify various forms of political exclusion in the West. As neoliberal inclusion efforts and processes of globalization blur the lines between the disabled and able-bodied in some contexts, transitions between able-bodied and disabled identities are sped up in other contexts. The “zone of fluidity” defines the ambiguous terrain where the previously able-bodied can become coded as disabled and the previously disabled can become “normatively” disabled, or represented as “able-bodied” by measure of their inclusion within the global economy. All of these shifts are made in relation to other forms of difference, including race, gender, class, and sexuality.

<sup>11</sup>For this section, I am indebted to Sheri Fink’s (2009) *New York Times* piece, “The Deadly Choices at Memorial.”

<sup>12</sup>Quoted in Dyson, 2007, p. 81.

<sup>13</sup>In their essay, "Natural Hazards, Human Vulnerability, and Disabling Societies: A Disaster for Disabled People," Laura Hemingway and Mark Priestley (2006) cite that "in 2000 more than 20%" of the population "were recorded as disabled in New Orleans, St Bernard, Jefferson, Hancock, and Jackson" (59).

Internet Justice: Reconceptualizing the Legal Rights of Persons with Disabilities to Promote  
Equal Access in the Age of Rapid Technological Change

Paul T. Jaeger, Ph.D., J.D.

Information Policy & Access Center, College of Information Studies, University of Maryland

**Abstract:** Although a range of laws and regulations have been created in the United States to promote online accessibility for persons with disabilities, tremendous disparities persist in access to Internet technologies and content. Such inaccessibility is an enormous barrier to equality and participation in society for persons with disabilities. The current legal approaches to online accessibility have not proven successful, focusing on specific technologies and technical solutions to accessibility. This paper argues for a reconceptualization of the approach to promoting legal guarantees of online access for persons with disabilities, focusing on information and communication goals, the processes of accessing information, and new approaches to monitoring, guidance, and enforcement. Without a broader conception of accessibility under the law, persons with disabilities risk being increasingly excluded from the technologies and content of the Internet that are coming to define social, educational, employment, and government interactions.

**Key Words:** Accessibility, Internet, Social Justice

A reflection on the approach of accessibility law is extremely important as the Internet has significantly changed and continues to rapidly alter information behavior, communication, education, government, entertainment, and virtually every other important human interaction. The Internet and related technologies – such as computers, mobile devices, software, websites, and social media tools, among many others – promise to make even more significant changes to life in the future. In technologically advanced societies, living life exclusively offline is already increasingly difficult. Registering a student for school, filing taxes, applying for social benefits, banking, and numerous other functions often require use of the Internet. In many cases these types of services are exclusively online. Additionally, many entertainment options and shopping resources exist only online. When there are physical and virtual equivalents, the online equivalent often offers lower prices, greater selection, home delivery, and other conveniences. The devices powered by the Internet have created new means of interaction and information resources that were unthinkable even ten years ago. Yet, the opportunities of the Internet are not equally available to all.

The federal government in the United States has passed a range of laws and created sets of regulations pertaining to online accessibility for persons with disabilities. These laws include Section 508 of the Rehabilitation Act, the Americans with Disabilities Act, the E-government Act, the Telecommunications Act of 1996, and the Twenty-first Century Communications and Video Accessibility Act. Nevertheless, levels of accessibility remain remarkably low in the technologies needed to access online content, including software, computers, and mobile devices, as well as in the content of the Internet, across governmental, commercial, and even non-profit web content. Numerous studies have demonstrated – and continue to demonstrate – the large barriers and severe inequalities that many people with disabilities encounter when using the Internet. As the reliance on online interactions, services, and resources continues to expand, the disparities in access will become increasingly isolating for people with disabilities.

All of these issues have been understood since the mid-1990s, but attention paid to these issues by governments, industry, and educators has never been sufficient. In the current environment, concerns about lack of equal access to the Internet encompass not only information gathering, but also communication, social interaction, the ability to seek and engage in education and employment, and participation in government. Being excluded from the Internet and related technologies makes an individual tremendously disadvantaged in society. The Internet has been both a liberating tool that provides increased access to information as well as the creator “of new or additional barriers to accessing information and the benefits of an information society” (Stienstra, Watzke, & Birch, 2007, p. 151).

In fact, a technology with social benefits to everyone other than persons with disabilities can be seen as active oppression of persons with disabilities (Goggin & Newell, 2000, 2003). Recent specific examples of these inequalities of access to Internet technologies and content that have significantly affected people with disabilities include inaccessible mobile devices, tablets, e-book readers, social media sites, webmail programs, online testing sites, and educational materials (e.g., Higgins, 2009; Howard, 2011; Lazar & Wentz, 2011; Parry, 2010; Portner, 2010; Qualters, 2009; Sadon, 2010; Wentz & Lazar, 2011).

The lowly status accorded to online accessibility in many corners is encapsulated in the strange fact that in 2010, the Department of Justice announced that it would be asking agencies if they were in compliance with the online accessibility requirements of Section 508 of the Rehabilitation Act (Gordon & Kundra, 2010). While this may sound like a positive action on the surface, Section 508 was passed in 1998 and was to have been fully implemented by 2001. Further, the government has not looked into Section 508 compliance since 2004, despite a parade of studies documenting that government agencies do not generally comply with Section 508 requirements, such as the studies discussed in the next section. Perhaps the most surprising aspect was that there was no intention to objectively assess the accessibility of the sites, but simply to ask the agencies to tell the Department of Justice how accessible the sites are.

The Department of Justice report detailing the findings of their study ([http://www.ada.gov/508/508\\_Report.htm](http://www.ada.gov/508/508_Report.htm)) was released in late 2011. The levels of compliance with the requirements of Section 508 reported by the agencies were revealing. About 58% of agencies reported performing any routine accessibility testing of their websites, 22% of agencies reported checking for accessibility only when notified of accessibility problems, and 12% reported never checking accessibility and not having any plans to do so. At least, 73% did report providing an email address to report accessibility problems on the website. Beyond websites, levels of accessibility testing are even lower, as 30% of agencies developing multimedia reported having a process to check it for accessibility. The findings of the study reflect long-term trends in the approaches of many government agencies to inclusion of people with disabilities – only focusing on accessibility after a problem is externally identified (Lazar & Jaeger, 2011; Wentz, Jaeger, & Lazar, 2011).

The range of laws and regulations created by the United States government for promoting online access for persons with disabilities are more robust and comprehensive than those of any other nation (Jaeger, 2004; Simpson, 2009). However, they are of little value if they are not

coherent and enforceable. It is long past time for a refocusing of disability advocacy and research on this vital topic, as it truly is one of the most important areas of equality for persons with disabilities. During the campaign for the implementation of closed captioning, the term “media justice” was employed by people with hearing impairments to convey the importance of equal access to the content of television programs for all (Downey, 2008). Drawing on this precedent, it is time for persons with all types of disabilities to begin asserting their rights to Internet justice as the foundation of social inclusion in the Internet age.

This paper explores the reasons that the rapid pace of change of online technology necessitates a reconceptualization of disability rights law, the new information and communication conceptual pillars of disability rights law that might address these inequalities, and potential ways in which these concepts could be implemented and enforced under the law. The goal of these changes is to promote a notion of Internet justice for persons with disabilities, a justice that eliminates the barriers preventing equal participation of persons with disabilities in many Internet-related technologies and in many aspects of the online content.

### Inaccessibility and the Internet

In the United States, 54.4 million people have a disability (18.7% of the overall population in 2005), while the number of persons with disabilities worldwide was projected to approach one billion in 2010 (Albrecht & Verbugge, 2000; Metts, 2000; US Census Bureau, 2008). Technologies that are inherently designed to be inclusive of all users regardless of ability – including the large portion of the population with a disability – are known as “accessible technologies.” To be accessible, a technology must be usable in an equal manner by all users without relying on specific senses or abilities. Additionally, the technology must be compatible with the assistive technologies that users may rely on: narrators, scanners, enlargement, voice-activated technologies, refreshable Braille, and many other devices that persons with disabilities may employ (Draffon, 2009; Jaeger, 2009; Lazar, 2006; Lazar & Greenridge, 2006; Lazar & Jaeger, 2011).

Online inaccessibility can affect most people with disabilities, depending on the types of inaccessibility encountered. To be inclusive of persons with visual impairments, a website must be designed so that all of the text, buttons, and links can be read by a screen reading program like JAWS or Window-Eyes; that all graphics have alt tags – text describing the image; that it has sufficient contrast between text and background; that it works with screen magnifiers, screen enlargement software, and Braille readers; that it can be navigated by keyboard rather than mouse; that text size and color contrast can be adjusted; and that the features with other types of assistive technologies that may be used for text size and color contrast.

For users with hearing impairments, all audio content on the website must have closed captioning or a textual equivalent. For users with seizure disorders, websites must avoid flashing items. For users with cognitive disabilities, the navigation of the site and instructions should be clear, while the layout must be uncluttered. Users with mobility impairments must be able to navigate without a mouse through voice and other alternate input devices; finally, compatibility with a range of assistive technologies is also extremely important.

Information technologies can be accessible from the outset if designed to include all users and if the accessibility solutions are designed to carry through subsequent generations of an information technology (Hackett, Parmento, & Zeng, 2004; Kennard & Lyle, 2001; Lazar & Greenidge, 2006; Stephanidis & Emailiani, 1999; Vanderheiden, 2003). However, for most information technologies, accessibility is not part of the design process and accessibility testing infrequently occurs in the development and implementation of most information technologies (Jaeger, 2006a; Kanayama, 2003; Keates & Clarkson, 2003; Theofanos & Redish, 2003; Tusler, 2005). As a result of this lack of focus on accessibility, the average time between the introduction of a new ICT and the availability of an accessible version is three years (Kanayama, 2003). The design of technologies – when not including accessibility as a core component – actually disables rather than enables, creating further social barriers for persons with disabilities (Goggin & Newell, 2003; Moser, 2006).

The resulting barriers to Internet accessibility are significant, and reflected in the levels of usage. In 2011, 54% of adults with disabilities used the Internet, while 81% of other adults did (Fox, 2011a, 2011b). People with disabilities who do regularly use the Internet also lag behind in quality of access, with 41% of adults with disabilities having broadband access at home, while 69% of the rest of the population does. Similarly, a 2010 study found that broadband adoption by persons with disabilities was two-thirds that of the national average and that people with disabilities who have broadband engage in a much smaller range of online activities as a result of accessibility issues (Horrigan, 2010). This smaller range of activities results directly from inaccessibility of online content and pathways to that content.

Early estimates of the inaccessibility of commercial websites ranged from 80% to 95%; a 2004 study found that 91% of e-commerce websites did not meet Section 508 accessibility criteria; and in 2009, more than 90% of leading corporate, non-profit, and e-commerce sites were found to have accessibility barriers (Loiacono & McCoy, 2004, 2006; Loiacono, Romano, & McCoy, 2009; Sullivan & Matson, 2000). Corporations still lag behind federal and state governments in website accessibility (Yu & Parmanto, 2011).

Collectively, the findings from all of these studies demonstrate that most corporations have not “sufficiently recognized the importance of customers with disabilities to their business goals” (Loiacono, 2004, p. 82). Many companies are not even aware of their requirements under accessibility laws. A 2010 study found that 40% of airlines are unaware of the accessibility requirements for air travel websites and call centers, while two major airlines did not even honor these requirements (Lazar *et al.*, 2010). A 2012 follow-up study found no notable progress in compliance with these requirements (Lazar *et al.*, 2012). The inattention to these requirements for airline websites are representative of a larger problem with lack of attention to accessibility issues in other uses of websites by corporations.

In employment, many processes in a job that might have made a position difficult or impossible for a person with a disability now can be negotiated with the help of computers, the Internet, and assistive technologies (Ritchie & Blanck, 2003). However, employment statistics actually show that the first few years after the passage of Section 508 actually paralleled declines in employment of persons with disabilities (Bound & Waidmann, 2002). A 2005 study found that 97% of companies use the Internet and online services as part of hiring and human resources



processes, yet only 13% of these companies were familiar with the guidelines for accessible website design, and only 10% could confirm that their online hiring and human resources materials had been evaluated for accessibility (Bruyere, Erickson, & Looy, 2005). Of the persons with disabilities who are employed, 90% rely on accessible technologies in their jobs (Johnson, 2004).

In government information online, the accessibility picture is no better. Though a key of focus for Section 508 was access to online government information and services, a wide range of studies over the course of a decade have shown low levels of compliance with the law by government agencies (for overviews, see Jaeger, 2011; Lazar & Jaeger, 2011). In fact, a comparison of different studies over the years reveals almost no progress in overall levels of accessibility of e-government websites between 2000 and 2010 (Olalere & Lazar, 2011; Lazar, Jaeger, & Bertot, 2011). The percentages of accessible government websites have barely changed in ten years, with percentages of accessible websites still commonly found in teens or twenties a decade after the Section 508 requirements were to have been implemented (Olalere & Lazar, 2011).

Almost 70% of elementary and secondary schools and 100% of post-secondary institutions require students to use the Internet for educational and administrative activities (Ogden & Menter, 2009). However, the accessibility of academic websites has steadily decreased since the passage of Section 508, and teachers are rarely prepared to handle the technical problems that students with disabilities face in accessing online course materials (Carlson, 2004; Harper & DeWaters, 2008). A 2010 overview of studies of higher education accessibility showed more than 75% of the sites examined to be inaccessible (Bradbard, Peters, & Caneva, 2010). While the Internet and online content offer numerous new opportunities for persons with disabilities in education, employment, social interaction, and civic engagement, these potential benefits will not be realized in a heavily inaccessible online environment.

These Internet-related challenges to participation add to significant existing social barriers. The rates of failure to complete high school are about three times higher among persons with disabilities than the rest of the population; among those who pursue higher education, one year after graduation, only 5% of students with disabilities remain enrolled in four-year colleges (Stodden, 2005; US Department of Education, 2010; Wagner, Newman, Cameto, Garza, & Levine, 2005). For most people with disabilities, higher education “is still just a dream” (Mates, 2010, n. p.). Persons with disabilities face unemployment at more than three times higher levels than the rest of the population (54.4% versus 16.5%) and suffer similar gaps in educational attainment (US Census Bureau, 2008). For some types of disability, the gaps in employment are even higher – for people considered to have a severe disability by the Census Bureau, 69.3% are unemployed and 27.1% live in poverty, three times the national average (US Census Bureau, 2008). As such, the threat of lack of equal access to the Internet looms as a catastrophic expansion of current barriers and exclusions from society for persons with disabilities.

#### Access, Accessibility, and the Law

In 1969, the United States Supreme Court explicitly stated, “The Constitution protects the right to receive information and ideas” (*Stanley v. Georgia*, 1969, p. 564). Although often an

unspoken element of the guarantees of the First Amendment, this right to receive, access, and communicate information ensures the ability to meaningfully participate in society (Jaeger & McClure, 2004; Mart, 2003; McIver, Birdsall, & Rasmussen, 2003). Information access and exchange – regardless of medium – is a matter of civil rights. However, for persons with disabilities, inaccessible Internet technologies and content undermine these civil rights related to information.

However, the approaches to disability rights laws to technology have never been focused on technology as a means of information access and exchange. Instead the laws are based on the specific nature of certain technologies, leaving the laws inapplicable to technological change (Crawford, 2003; Frieden, 2003). By focusing on specific technologies and ignoring the underlying reasons that make accessibility a social necessity for persons with disabilities, the current conceptual approach to the law all but guarantees that online accessibility will not be achieved.

These inherent biases against online accessibility in the law also include two other key elements. First, disability rights laws in the United States have been built on an “antissubordination approach,” meaning that rights are available only if to those who are members of the legally defined class of people protected (Colker, 2005). In contrast, all other types of civil rights laws in the United States are based on an “antidifferentiation approach,” meaning that anyone has protections under the law if they are being discriminated against (Colker, 2005). This difference means that disability rights laws are much harder to enforce, as people with disabilities must first prove that they have standing under the law, something no other population must do under civil rights laws. This need to establish standing creates what has been labeled the “Goldilocks dilemma,” allowing courts to dismiss the claims of persons with disabilities who the courts determine are not qualified under the law unless they are of a “just right” level of disability (Areheart, 2008). Courts at all levels have enthusiastically embraced this option, significantly limiting the ability to enforce accessibility rights (Areheart, 2008; Davis, 2002; Lee, 2003; Switzer, 2003).

The second and closely related problem is that the law also has many exceptions, loopholes, and inherent contradictions in information and technology; these serve to increase and even encourage discrimination against persons with disabilities. There is an exemption written in many of the disability laws for an “undue burden,” which exempts the creation of accessible versions of products if such accessibility would be too costly or too time-consuming, with clearly defining these terms. As such, many corporations have used the undue burden exemption as a reason for not making accessible versions of technologies (Dispenza, 2002; Jaeger, 2006a; Kanayama, 2003; Lazar & Jaeger, 2011).

Yet, reliance on industry standards is insufficient to promote accessibility (Stienstra, 2006), and disability rights laws cannot be revised fast enough to match technological change at this point. Even if the political capital and will existed, legislation and rulemaking move too slowly to catch up to the pace of change in the online environment. To address this accessibility conundrum, disability law needs to be reconceptualized expressly to ensure ongoing equal access to the online technologies and content.

Thus far, the common perspective on disability and the Internet has been to apply pre-Internet approaches to contemporary problems (Goggin & Newell, 2006). However, the law related to information and technology access needs to better reflect the realities of the current environment and the inevitability of ongoing, significant technological change. Simply put, the law needs to focus on information and communication goals to promote social inclusion rather than just creating technical standards or performance metrics. Such an evolution in the conceptual foundations of disability rights law is vital to ensuring that persons with disabilities are able to participate in society.

Due to the rapid technological changes in the past two decades, staying engaged in society is moving from Internet access being necessary just for information access to Internet access being necessary for information access, communication, and social interaction (Jaeger & Xie, 2008). In considering the ways in which the law could move to promote sustained equality of access, the constantly evolving nature of the Internet and related technologies must be considered. Even an update to an existing technology may change the accessibility of the technology or the ways in which the user interacts through assistive technologies. Equality of access depends on equality of all levels of access. Until the complex nature of information access is embodied in disability right laws, these laws will not be able to promote meaningful online accessibility.

There are three types of access to information – physical access, intellectual access, and social access (Burnett, Jaeger, & Thompson, 2008; Jaeger & Burnett, 2010). Physical access is the most basic and familiar aspect in disability rights law – the ability to reach something, in this case information. Physical access to information is generally viewed as access to the document or other form embodying information, whether conveyed through print, electronic, verbal, or another means of communication – literally the process of getting to the information that is being sought (Svenonius, 2000). The vast majority of discourse on information access tends to focus on physical issues, such as the physical structures that contain information, the electronic structures that contain information and the paths that are traveled to get to information (Jaeger & Bowman, 2005). While it is a necessary prerequisite, mere physical access is not sufficient for full access. “It is a common, but mistaken, assumption that access to technology equals access to information” (McCreadie & Rice, 1999, p. 51). The ability of a user to get to information and the ability of that user to employ information to accomplish particular goals are very different (Culnan, 1983, 1984, 1985).

The next level of access is intellectual access – the ability to understand the information. Intellectual access can be understood as the accessing of the information itself after physical access has been obtained (Svenonius, 2000). Intellectual access to information “entails equal opportunity to understand intellectual content and pathways to that content” (Jaeger & Bowman, 2005, p. 68). Issues of intellectual access involve an understanding of how the information is presented to people seeking information, as well as the impact of such presentation on the process of information seeking; intellectual access to information includes the means through which the information is categorized, organized, displayed, and represented.

Social access – the ability to communicate and use the information in social contexts – is the most advanced level of access (Burnett, Jaeger, & Thompson, 2008). Such social contexts

can range from personal communication for entertainment purposes to educational and work settings to democratic participation. Gaining and understanding information without the ability to communicate that information prevents social engagement through the information. Social access is now heavily dependent on the online environment for communication in many contexts. The social access depends both on individual user's attitude toward the Internet and on the ability of the user to employ the Internet and related technologies to engage in social interactions.

The laws that have been implemented to promote accessibility generally focus on the physical access issues (Bowe, 1993). A clear example of this trend can be found in closed captioning. The current law mandates that closed captioning be available, without considering the types of content or levels of content that would be available in that format. As a result, a large amount of closed captioning text is rewritten to reflect a much lower reading level than the spoken words, demonstrating a lack of consideration of intellectual access, and the types of programming available with closed captioning have varied widely in usefulness and educational value, evidencing a lack of consideration of social access (Downey, 2008, 2010). As a result of this focus on physical access, even the training materials to assist developers in the creation of accessible technologies reflect this strong bias toward physical access (Law, Jaeger, & McKay, 2010).

On the Internet, a similar focus on physical access can be seen in Section 508 of the Rehabilitation Act, which is intended to ensure equal access to government information technologies and online content. Studies have shown low levels of compliance with the law (Dobransky & Hargittai, 2006; Ellison, 2004; Jaeger, 2006b; 2008; Lazar & Greenidge, 2006; Rubaii-Barrett & Wise, 2008). Both the Federal Communications Commission's *National Broadband Plan* and the National Council on Disability's *National Disability Policy: A Progress Report* recently noted the widespread failure of the federal government to comply with Section 508 requirements, with the later report paralleling non-compliance with Section 508 to the common inaccessibility of commercial websites (Federal Communications Commission, 2010; National Council on Disability, 2009). However, even full compliance would not address many of the access issues for persons with disabilities.

The Section 508 guidelines focus on physical access for persons with disabilities, emphasizing visual, hearing, and motor impairments, but mostly leaving out cognitive impairments (Jaeger & Bowman, 2005; Lazar, 2007; Lazar & Jaeger, 2011). This focus of the law on physical access results in limited consideration of intellectual and social dimensions of access. Compliance with Section 508 means that a website, software application, or operating system can technically be accessed by someone using an assistive technology input or output device. Technical accessibility, however, does not necessarily equate to an interface that is usable, understandable, or functional for communication (Theofanos & Redish, 2003). Without these later components, a technology can be technically accessible under the law and virtually preclude intellectual and social access for some or all persons with disabilities. For social equality to be achieved in access to the Internet, disability rights laws will need to place greater emphasis on achieving intellectual and social access – along with physical access – online.

Issues of online accessibility for persons with disabilities exist within a much broader policy context, and within this context, online accessibility is part of a set of issues resulting from a failure of policy harmonization. The increasingly rapid pace of technological change has resulted in many gaps between policy and technology, as well as gaps between different policies related to one technology. As policy struggles to stay relevant to new technologies, a key issue will be policy harmonization – the addressing of incomplete, inconsistent, and conflicting policies related to information and communication technologies (Bertot *et al*, 2009; Shuler, Jaeger, & Bertot, 2010). The challenges of policy harmonization are most prominent in the online environment, which are dependent on these technologies and where technological change is most rapid (Bertot, Jaeger, & Grimes, in press; Bertot, Jaeger, & Hansen, in press; Shuler, Jaeger, & Bertot, 2010).

In terms of online accessibility, many scholars have noted clear gaps between laws related to disability and the technological realities of the Internet; many legal commentators offered proposed solutions following the 2006 decision in the *National Federation of the Blind v. Target* case that held that e-commerce only has to be accessible if it sufficiently similar to a physical store. Evidencing a clear lack of understanding of technology and its social implications, the holding at least served to increase awareness of inaccessibility among legal scholars. A range of approaches were suggested, including, emphasizing a plain language interpretation of existing disability-rights laws to increase online accessibility, making text accessible and allowing other content to be inaccessible, regulating the Internet as if it were a telephone system, and having Congress pass another law specifically for online accessibility (e.g., Abrar & Dingle, 2009; Bashaw, 2008; Else, 2008; Kessling, 2008). The proposed solutions following the *National Federation of the Blind v. Target* generally overlooked the realities of enforcement of accessibility laws and/or the fact that technological change would render the proposed solutions quickly outdated.

More recently, the federal government engaged in efforts to harmonize accessibility laws. The Department of Justice (2010a) began pursuing a series of revisions to the ADA to account for changes in technology and society since the passage of the law, including website accessibility. The intent is to officially extend website accessibility requirements to all entities covered by the ADA, including local governments, state governments, and places of public accommodation. Applying the ADA to entertainment and commerce online would hopefully resolve many problems of inaccessibility and the problems created by the *Target* holding. A key part of the debate on improving the guidelines was the question of whether website accessibility for persons with disabilities should be based on performance standards (focusing how something works) or technical standards (focusing on how something is designed) (Department of Justice, 2010b).

Contemporaneously, the Architectural and Transportation Barriers Compliance Board – better known as the Access Board – began pursuing new regulations under Section 508 of the Rehabilitation Act and the accessibility provisions of the Telecommunications Act (Access Board, 2010a, 2010b). The first goal was to update the regulations to bring them in harmony across the laws. The second goal of these new regulations was to change the focus of the accessibility requirements from product type to functionality of a technology, accounting for the range of functions now embodied in many products. These changes represent a move from

technical standards to performance standards. In late 2011, the Access Board issues their proposed new rules for Sections 508 (<http://www.access-board.gov/news/ict-draft-rule.htm>).

While performance standards are the option more likely to produce accessible technologies than technical standards (Corcoran, 2011), neither of these approaches addresses the inherent structural issues with monitoring, compliance, and enforcement or larger conceptual issues of access. In both of these cases, the proposed new regulations would have significant impacts on online accessibility, but any impacts would only occur if the new regulations are monitored and enforced to ensure compliance. Nothing in these regulations would make significant changes in monitoring and enforcement approaches or activities, following the existing structures that have not produced an accessible online environment. Based on past precedent, it seems unlikely that these new regulations would result in widespread online accessibility. Additionally, neither new set of guidelines would sufficiently shift the focus to the overall goal of equality of access. While performance-based criteria would better account for considerations of physical access, the far more complex challenges of equality of intellectual and social access stretch far beyond the technical or performance-based standards under consideration.

Without more holistic changes, the situation is unlikely to significantly improve, regardless of the types of standards created. These limitations of the current approach in responding to technological change were evidenced in two other recent actions by the federal government related to accessibility. Congress passed the Twenty-first Century Communications and Video Accessibility Act of 2010, but, in spite of its title, the law was devoted to retroactive fixes to existing technologies, some of which had been widely used for half a century. At the same time, the Departments of Education and Justice (2010) stated that elementary, secondary, and postsecondary institutions were not allowed to use inaccessible e-book readers under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (*Settlement Agreement*, 2010). In both of these cases, legislation and enforcement lag far behind the technologies being used, offering at best delayed access.

To move beyond the Sisyphean cycle of persons with disabilities perpetually waiting for accessibility, changes to regulations or policy harmonization will not be sufficient. What is needed is a new approach, one which focuses on the ultimate outcome – equal access online for persons with disabilities – and is based on the methods most likely to produce the desired outcome. Such an approach would require significant structural changes to achieve goals of equality of access, resulting in a very different approach to monitoring, compliance, and enforcement than those previously taken in pursuit of disability rights. Simply put, the pursuit of Internet justice for person with disabilities will require an innovative approach to civil rights oversight.

### Implementing and Enforcing Internet Justice

It has been suggested that the most effective Internet policy might be that which learns from core principles of the online environment, one of which is fairness (Margetts, 2009). For persons with disabilities, fairness is missing from both the policy and the practice of the Internet. While the greater attention paid by the Obama administration to accessibility has resulted in an

expansion of some of the technologies covered and increased efforts for accessibility among government agencies, these efforts use the same underlying approach that has yet to result in equitable access for persons with disabilities (Jaeger, 2011; Lazar & Jaeger, 2011). In order for online accessibility to truly be guaranteed for persons with disabilities, the key conceptual problems detailed above must be addressed in ways that have not been a part of accessibility law and regulation to this point.

To achieve true equality of access to the Internet and related technologies under the law, the legal guarantees of access need to be reconceptualized to simultaneously focus on ensuring physical, intellectual, and social access to information and technologies in addition to the creation of technical accessibility standards that are not tied to specific technologies. There are several key areas that could be emphasized in the law to increase the focus on Internet justice to promote physical, intellectual, and social access. These elements encompass redefining disability, ensuring equal access, and providing better education about disability. The foundation of Internet justice, however, relies on the creation of an organization that can serve to implement, monitor, and enforce equality of access for persons with disabilities.

Such an organization could embrace several foundational principles that would be key to guaranteeing Internet justice:

1. **Coordination and Harmonization:** This one organization could harmonize all of the activities necessary to guaranteeing Internet justice, being empowered to produce guidance and regulations, to draft and monitor accessibility requirements, conduct accessibility research, support innovation in accessibility, and enforce accessibility requirements. Such an organization could be located in any of a number of agencies, though being a part of the DOJ would probably be a real source of strength. The agency could be headed by a Chief Accessibility Officer (CAO), a position that already exists in many forward-thinking technology companies (Lazar & Jaeger, 2011). An organization of this nature would facilitate the type of harmonization of uncoordinated accessibility laws and regulations that the DOJ and Access Board have recently begun.
2. **Monitoring and Enforcement:** Perhaps the greatest failing of the legal approach taken in the United States toward accessibility has been the lack of an effective enforcement mechanism for accessibility. By giving people with disabilities the responsibility to monitor accessibility and bring complaints and claims against agencies and companies that violate accessibility laws, the burden has been placed on people with disabilities to enforce their own rights in a way that no other minority or traditionally disadvantaged group does (Colker, 2005). As disability rights laws allow public and private entities to claim the requested accommodation is not financially or practically reasonable and therefore an undue burden under the law, most accommodations never occur due to claims that they represent too much effort in terms of time or cost. A government agency overseeing online accessibility would solve the problems in both of these cases, with the government taking responsibility for monitoring and enforcement of accessibility problems.
3. **Guidance and Leadership:** By bringing together the drafting, monitoring, and enforcement of requirements, it would be the clear responsibility of one organization to

ensure equal access to the Internet and related technologies for persons with disabilities. Government, non-profit, and commercial entities would know where to turn for requirements and for guidance to meet those requirements. This approach would also alleviate the unique responsibility, expense, and effort placed on people with disabilities of trying to enforce their own civil rights. A single organization would serve as the place to receive accessibility complaints and pursue those complaints as the party charged with enforcement. The new organization would have its own testing and research facilities to perform comprehensive evaluations of technologies and websites that are the focus of accessibility complaints.

4. **Access Considerations:** To accompany the consolidation of online accessibility responsibilities into a single government organization, the existing requirements for accessibility would need to be reconsidered and strengthened. Such new requirements would need to be developed with the direct input from people with disabilities and disability rights organizations that represent the spectrum of different disabilities. The newly conceived regulations would focus on the information and communication needs of users with disabilities rather than on specific technological or performance issues.

Requirements developed from this perspective would account for the physical, intellectual, and social dimensions of accessibility and the range of needs of people with different kinds of disabilities. This approach would shift the focus away from technical concerns to social concerns with technological components. Following upon a broader, more inclusive understanding of disability and all of the access needs that are essential components of participation in society in an age of rapid technological change, requirements would account for the full range of physical and cognitive disabilities and the physical, intellectual, and social access needs that accompany this full range of disabilities.

These types of requirements would focus on access and social justice outcomes, avoiding the problem of the requirements being far behind the current technologies. The access goals would remain the same as the technologies changed. The concept of Internet justice rests on such a significant shift in the basic legal understanding of disability.

The access requirements would need to cover both hardware, software, and content. The most basic change this approach would result in is the firm requirement that technologies be designed to be inherently accessible from the outset, with no new inaccessible products being allowed to reach the market. Mandating that online technologies address the physical, intellectual, and social dimensions of accessibility for individuals with disabilities would mean that all technologies related to the Internet would have to be made accessible to be made available. These requirements would apply both to new versions of existing technologies and ones that have not yet been developed. The current average multi-year gap between an online technology being introduced and an accessible version being made available renders most accessible versions of online technologies so far out-of-date as to be utterly useless.

5. **Technical Dimensions:** The requirements produced by the agency would also include clear technical standards, articulating who will benefit from the requirements and the importance of accessibility to those populations; specific guidance and instructions for



website developers and webmasters; monitoring, testing, and compliance-oriented technical assistance programs; and explanations of enforcement mechanism and clear sanctions for failure to provide accessible technologies. As part of this new set of requirements, the possibility of claiming undue burden on new products would disappear.

If a new Internet-related technology is to be available to the public, it would be equally available to all members of the public. Meaningful enforcement of the new accessibility requirements must be a central consideration for this organization. To ensure the laws and guidelines are actually complied with, such an agency would need meaningful monitoring and enforcement powers over both government and corporations.

The requirements would also extend beyond the creation of technologies themselves to encompass all elements of online information, communication, and interaction. As online social networks and other online interactions are becoming a pillar of interpersonal communication, education, employment, and civic participation, persons with disabilities need to be included in these tools and communities (Anderson & Jonsson, 2005; Bowker & Tuffin, 2002; Jaeger & Xie, 2008).

In fact, social networks related to disability are a preferred online destination for many persons with disabilities (Guo, Bricout, & Huang, 2005; Seymour & Lupton, 2004). The move toward a focus on communication and interaction as the primary uses of the Internet necessitates that social networks and other forms of online communication must also be explicitly accountable under the new requirements. Ultimately, these new requirements would serve to change the overall approach to the development of both Internet technologies and online content.

6. **Research and Education:** The organization would need authority to promote accessibility to help entities deal with the stricter online accessibility requirements. To promote innovation and new designs in accessibility, the organization would need funding to support research. Currently, research spending on disability is woefully inadequate, with only small amounts of grant money available for Internet-related accessibility research from a disparate set of government sources. Additionally, the organization would need a set of further inducements at its disposal to promote and reward the focus on Internet accessibility in the public and private sector, such as merit recognitions, seals of approval, and tax credits.

The organization would also support accessibility development by providing best practice guides, developer handbooks, and other instructional materials for including accessibility in the design, development, and implementation processes. The organization would try to reach managers and developers, as well as the public in general, to provide meaningful education about the social importance of Internet accessibility and the benefits to individual companies and government agencies and to society as a whole. Education specifically about the importance of Internet justice would accompany the reconceptualization of the laws, as organizational acceptance of accessibility is heavily reliant on acceptance by leaders and managers within an organization (Jaeger & Matteson, 2009).

7. **Social Inclusion:** The changes that could derive from such a government agency with this mandate would likely extend far beyond increased accessibility online. The increased access would create greater opportunities in education, employment, communication, social interaction, entertainment, and civic participation, which could greatly improve the opportunities for and the inclusion of people with disabilities in physical and virtual society. Truly guaranteeing people with disabilities an equal place online could greatly alter the ways in which people with disabilities are perceived, treated, and included in society, in both the physical world and the online world. Working toward achieving Internet justice in this manner could also serve as a test case for the implementation, monitoring, and enforcement of disability rights in other areas. If this approach is successful, a more consolidated approach to disability rights could be employed in other aspects of society.
8. **Building on Past Successes:** The United States government is uniquely positioned to create an agency that could successfully address issues of online equality. As the nation that has led the way in the formalization of legal rights for persons with disabilities, this approach is in keeping with past innovations and accomplishments. For all of the gaps in the law discussed above, the United States still has the strongest and most specific set of disability rights laws internationally (Jaeger, 2011). Guaranteeing Internet justice to persons with disabilities in the twenty-first century would be as significant and necessary as guaranteeing a right to a free public education for students with disabilities in the 1970s. Further, as the United States has a comprehensive, national set of disability rights laws, it would have a better chance of succeeding at such a major reconceptualization than a nation with decentralized, state- or province-based disability rights laws, where implementations tend to be far less standard and less frequently applied, or a nation with greater numbers of exclusions to their laws, or a nation where compliance is voluntary, or a nation where standards are created by industry (e.g., Barnes & Mercer, 2003; Burns & Gordon, 2010; Gulliksen, Alexson, Persson, & Goransson, 2010; Stienstra, 2006).

There are likely other key principles of Internet justice beyond those detailed above that would become evident with greater discourse around the issue and if the concept were to be incorporated into the law and other areas. However, these foundational elements could serve as the basis of improving and ensuring Internet justice for persons with disabilities as rapid technological change makes equal access to the technologies and content of the Internet ever more important for participation in society. Changing the laws to embrace the concept of Internet justice would take time and effort, but such changes are necessary to ensure long-term social inclusion of persons with disabilities.

### Conclusion

The age of rapid technological change needs a broader, more affirmative concept of disability rights under the law to ensure access to the technologies and content of the Internet that are now the lifeblood of employment, education, interaction, communication, and participation in government and society. The pace of development of information technologies renders inadequate the notion of purely technical or performance-based standards that are slowly updated to account for new technologies. A retroactive approach to Internet accessibility will never catch up to new devices and content, while performance-based standards do not capture the

complexities of the levels of information access, particularly intellectual and social access considerations. In either case, new regulations alone, whether technical or performance-based, will never lead to the holistic changes in guidance, implementation, monitoring, and enforcement that are necessary for Internet justice to be achieved.

Assertions of Internet justice through the law should become central to discourse and advocacy if persons with disabilities are to have a meaningful role in a society that is ever more dependent on the Internet and related technologies. If these changes are to be accomplished, it is imperative for disability rights organizations and disability studies scholars to concentrate efforts on this issue. Historically, disability rights causes in the United States have been most successful when disability rights organizations have coordinated their efforts (Barnartt & Scotch, 2001; Fleischer & Zames, 2001; Scotch, 2001). Given all of the potential negative social, educational, and economic consequences of an inaccessible Internet, it behooves everyone concerned about equality and social inclusion for persons with disabilities to contribute to advocating for Internet justice.

**Paul T. Jaeger, Ph.D., J.D.**, is Associate Professor and Diversity Officer of the College of Information Studies and Co-Director of the Information Policy and Access Center (<http://ipac.umd.edu>) at the University of Maryland, as well as Co-Editor of *Library Quarterly*, Co-Editor of the *Information Policy Book Series* from MIT Press, and Associate Editor of *Government Information Quarterly*. The author of more than one hundred and thirty journal articles and book chapters, along with seven books, Dr. Jaeger's research focuses on the ways in which law and public policy shape information behavior, particularly for underserved populations.

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## DISABILITY STUDIES BOOK AND MEDIA REVIEWS

### Book Review

**Title:** *Jumpstarting Communication Skills in Children with Autism: A Parents' Guide to Applied Verbal Behavior*

**Authors:** Mary Jane Weiss, Ph.D., BCBA-D & Valbona Demiri, Ph.D., BCBA-D

**Publisher:** Bethesda, MD, Woodbine House, Inc., 2011

**Cost:** Softcover; \$21.95; ISBN: 978-890627-70-6, 207 pages

**Reviewer:** Landry Fukunaga, M.A.

Individuals with autism experience a range of social and communicative deficits that may make day-to-day interactions with parents, siblings, peers, teachers, and professionals challenging. To address these challenges, many interventions focus on enhancing the functional communication skills of this population. For families of a child diagnosed with Autism Spectrum Disorder (ASD), navigating the array of services, intervention strategies, and treatment options can be overwhelming. *Jumpstarting Communication Skills in Children with Autism: A Parents' Guide to Applied Verbal Behavior* is intended as an introduction to one intervention strategy for parents of children between the ages of 15 months and 10 years.

Applied Behavior Analysis (ABA) utilizes a scientific approach to collect observable data to support or negate the effectiveness of specific interventions with children with autism. Specifically, this book focuses on applying ABA to increase communication skills and introduces other intervention strategies such as alternative communication systems, video modeling, and social stories. Information is presented in a practical manner and covers sufficient depth to be useful to any individual involved in building the communication skills of a person with autism including but not limited to parents, family members, teachers, and professionals. As many psychological, speech, and linguistic terms and theories are new to parents, the authors are careful to provide clear and accurate descriptions of each. The examples of challenges experienced by particular children and families are especially helpful in illustrating how communication deficits present in individuals with autism. The authors also explain possible functions of repetitive speech, echolalia, and perseverative interests to help parents understand why their children engage in such behaviors, provide interventions to consider, and address common misconceptions regarding alternative communication systems.

I would recommend this book highly as a practical introduction and reference for new professionals, students, teachers, and educated parents. This book helps to demystify interventions for individuals with autism and explain how professionals set treatment goals, collect data, and make adjustments as skills increase. In addition to ABA approaches, the authors introduce several techniques such as video modeling, video self-modeling, and social stores. Using a variety of creative approaches to working with children with autism can help parents and professionals understand the child's preference and what produces the greatest results.

While reasonably priced for professionals and many families, the book might reach a broader range of families with children with autism if it were less than twenty dollars. Families may also have wanted the authors to spend more time discussing how they might begin an intervention strategy at home, what data they might collect feasibly, and how that data might determine their next steps. This book is accessible to highly educated individuals with good English communication skills as the use of jargon may not be familiar or manageable for all families. The content could also be strengthened through addressing the range of therapies used to address speech and communication difficulties to help parents to be informed consumers who choose specific therapies based on need, fit, and preference.

*Jumpstarting* is useful to disability studies as the authors are careful to focus on functions that both desirable and challenging behaviors serve and the needs they fulfill. In this sense, the focus is on the individual and how that person can continue to get their needs met through an expanded array of communication skills or replacement behaviors for a disruptive perseveration. The authors specifically acknowledge that parents may be juggling a number of tasks and children, which makes it important to ask and receive assistance to allow parents time to implement interventions in a constant and consistent manner.

**Landry L. Fukunaga**, M. A. in Psychology, worked as a behavioral specialist and autism therapist for individuals with autism for five years in the state of Hawai‘i and in the field of disability studies for eight years at the University of Hawai‘i at Manoa. She currently works as an evaluator of educational programs focused on serving diverse student populations and can be contacted at [lfukunag@hawaii.edu](mailto:lfukunag@hawaii.edu).

## DVD Review

**Title:** *Down Under Mystery Tour Educational Pack*

**Producer:** Michael Noonan

**Publisher:** 2010 Boom-in-Shot Productions, Australia; Distributed by Mental Leap PTY LTD

**Cost:** Educational pack (5 discs) \$425 Single disc \$29.95 available at <http://www.downundermysterytour.com/>

**Reviewer:** Martha Guinan, MPH

*Down Under Mystery Tour* (2009) was conceived as part of Australian director/producer Michael Noonan's doctoral study about disability and comedy, which sought to explore the complex line between "laughing at" and "laughing with". The educational pack, completed in 2010, included Noonan's dissertation and additional materials related to topics created through the film.

The movie itself, *Down Under Mystery Tour*, is a comedy about Malcolm, who wants to create a "good TV show" as he hears there is money in it and does not like what he sees on his TV. He writes a script including his interests, hot babes and mystery, and sends it to several producers. One picks it up and starts to work with Malcolm to get it filmed. As happens to many films, the story alters slightly as the producer inserts her ideas and values. The lead actors are changed from two "hot chicky babes" to two men with disabilities. Malcolm, of course, does not like this and tries to get the actors to quit when he finds he cannot fire them. The movie is charming and funny with some raucous bits that can be off-putting.

Although generally I am not a fan of comedies, I found this movie engaging. Comedians tend to make fun of their shortcomings and these actors did the same without ridiculing themselves. I felt that the movie was true to the disabilities it portrayed. A wide audience should enjoy this movie; however the uncensored sexual comments may earn the film an "R" rating, limiting the potential audience.

Noonan, the director, learned about disabilities when he was first contacted to do a documentary about the adventures of a group of people with disabilities traveling to Egypt. *Unlikely Travellers* (2007) is included in the educational pack and is a delightful film that illustrates the joy the trip brought to the travelers. The group consisted of six people with disabilities and six without. The first half of the movie documents the physical and emotional preparation for the trip to Egypt; the second half focuses on the trip itself and its consequences. This journey is a collective step into the unknown that changed the lives of each of the adventurers. I especially enjoyed this movie as disability issues were presented as matter of fact and did not dwell on limitations or inabilities.

From this foray into disabilities, Noonan got the idea to combine his dissertation with a movie about laughter and disabilities. Comedy was an area Noonan was drawn to, and he thought it would be provocative when combining it with disabilities. Noonan got more than he bargained for when, during his dissertation proposal, two professors protested and publicly

denounced the project as demeaning and exploitive of people with disabilities. This in turn ignited an international media controversy around free speech and censorship.

The educational materials in the pack include lesson plans and video discussions around topics brought up in the film including sexuality and disabilities; attitudes about disability; disability and comedy; and actors playing disability. The lesson plans are well done and the discussions are interesting. The materials are best broken into small segments and tackled individually. This compilation documents and extends the existing knowledge of the field of disability studies as it values the opinions of the people with disabilities involved in the project. While the educational pack is quite pricey for the general population it would be a valuable tool in the disabilities studies classroom.

**Martha Guinan**, MPH, University of Hawai`i Center on Disability Studies, is a PhD. Student in Exceptionalities at the University of Hawai`i and works for the Center on Disability Studies. She is also the mother of an exceptional young actor named Ryan.



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### **About the Center on Disability Studies**

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

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

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

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

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