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## From the Editor's Desk: Introducing Associate Editor, Alex Lubet

We are pleased to announce that Alex Lubet has joined *RDS* as Associate Editor. Alex is charged with managing *RDS* forums. If you are interested in guest editing a forum, please contact Alex at lubet001@umn.edu.

Alex Lubet, Ph.D., is Morse Alumni/Graduate & Professional Distinguished Teaching Professor of Music at the University of Minnesota. He holds additional appointments as Director of Undergraduate Studies in the U of M Center for Jewish Studies and as Adjunct Professor of American Studies. He is also chair of the system-wide Senate Disability Issues Committee.

Alex is a founding member of the Editorial Board and frequent contributor to *RDS*. His writings also appear in publications including *Disability Studies Quarterly*, *Medical Problems of Performing Artists*, *Ethnomusicology*, and *Annual Review of Jazz Studies*. His essay "Richard Wagner and Disability Studies" will appear in September 2007 in *Richard Wagner for the New Millennium* (Palgrave), which he is co-editing with Matthew Bribitzer-Stull and Gottfried Wagner.

Alex is also a composer, performer, and writer for the stage. His musical and dramatic works have received over 400 performances on six continents. He is currently recording two CD's of original music for solo acoustic guitar for the MMC label.

Welcome Alex, in your new capacity as Associate Editor of RDS!

Cripping School Curricula: 20 Ways to Re-Teach Disability
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**Abstract:** As instructors of a graduate level course about using film to re-teach disability, we deliberately set out to "crip" typical school curricula from kindergarten through twelfth grade. Utilizing disability studies to open up alternative understandings and reconceptualizations of disability, we explored feature films and documentaries, juxtaposing them with commonplace texts and activities found in school curricula. In doing so, we sought to challenge any simplistic notions of disability and instead cultivate knowledge of a powerful, and largely misunderstood aspect of human experience. The article incorporates twenty suggestions to re-teach disability that arose from the course. These ideas provide educators and other individuals with a set of pedagogical tools and approaches to enrich, complicate, challenge, clarify, and above all, *expand* narrowly perceived and defined conceptions of disability found within the discourse of schooling.

**Key Words:** media, curriculum, disability studies in education

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

As instructors of a graduate level course on using film to re-teach disability, we deliberately set out to crip school curricula from kindergarten through twelfth grade. Historically, representations of people with disabilities in film have been characterized as damaging, restrictive, stereotypic, pessimistic, and inaccurate (Norden, 1994; Safran, 1998a; Safran, 1998b). Acknowledging the profound degree of influence film exerts on the public's consciousness, we actively seek to challenge such depictions. Using the insights of disability studies to open up alternative understandings and reframings of disability, we explore feature films and documentaries, juxtaposing them with typical texts and activities found in school curricula. In doing so, we ask questions that deliberately seek to complicate any simplistic notions of disability, and reveal it to be a rich, powerful, and misunderstood aspect of the human experience.

In our own experiences, the concept of disability in "mainstream" school curricula is overwhelmingly associated with shame and stigmatization, echoed in narratives and experiences of other students (Connor, 2006; Mooney & Cole, 2000; Rodis, Garrod, & Boscardin, 2001; Ware, 2001). Yet we also know that for many people, disability is claimed with pride (Linton, 1998; Mooney & Cole, 2000). Traditionally, special education has been dominated by the medical model of disability, primarily casting disability as a deficit inherent within an individual; a "problem" in need of scientific "examination," "diagnosis," and "treatment" (Berninger, Dunn, Lin, & Shimada, 2004).

Over the past decade, this way of thinking has been challenged by different models of understanding, including discursive framings (Reid & Valle, 2004), socio-cultural perspectives (Torres-Velasquez, 2000), and constructivist standpoints (Danforth & Smith, 2005). While the hegemony of the medical model still prevails, it is gradually becoming weakened by the persuasiveness of alternative understandings of disability which overlap and often coalesce within the domain of what is known as the social model of disability (Linton, 1998).

The social model focuses on disability as a culturally determined phenomenon, specific to cultural norms and expectations. Bearing this in mind, what follows are twenty ways that we believe educators can enrich, complicate, challenge, clarify, and continue to expand what we consider the positive redirection of longstanding negative conceptualizations of disability found within traditional special education (Brantlinger, 2004). Thus, our focus is on increasing options within reach of educators to teach disability in complex, varied ways, and reaffirming it as an inevitable and natural part of human diversity.

## 1. Teach "difference."

Introduce the notion that differences are often perceived subjectively. Furthermore, the person perceived as different (whether based on race, class, ethnicity, gender, age, body size, etc.) is neither better nor worse than the beholder. Add "disability" to this list. Compare and contrast how non-disabled people view people with disabilities versus how people with disabilities view themselves, thereby challenging notions of inferiority, incompleteness, unhappiness, and general *inability*. In addition, include the complex notion of how stereotyped people are vulnerable to the internalization of cultural biases and ways in which their resistance is exercised to transcend limitations imposed upon them (Asch, 1984; Hahn, 1988).

## 2. Discuss disability-related language.

Examine its widespread use at all levels of our society. Examples include: "That idea is so lame", "That's retarded", "Are you deaf?", "What a limp response", "Can I ask a dumb question?", "Are you blind?", "He's crazy", "She's insane", "Schizophrenic!", "Another case of the blind leading the blind", "I was paralyzed with fear", etc. What are the associations made with disability and the implications of these associations? Should this language be acceptable? What do disabled people think about non-disabled people using this language? What are some alternative ways of expressing the same thoughts without using disability as a "put-down" (Mairs, 1986)?

## 3. Contemplate disability as a minority label.

Explore whether the status of disability belongs with other "markers of identity" that have come to constitute minority group status; such as race, ethnicity, gender, sexual orientation, and class (Omansky-Gordon & Rosenblum, 2001). If people with disabilities claim kinship as a minority group, how does that change the way they perceive themselves and are perceived by others? What are some inequities in society that people with disabilities face? How can these inequities be addressed? How have disabled people and their allies addressed these inequalities?

# 4. Study the meaning of the words "able" and "disabled."

Ask: What does it mean to be able-bodied? What are able-bodied people "able" to do? This question is not a trick! In brief, able-bodied people have the luxury of not having to think about this question; most take for granted their status of having full access to most aspects of the world, feeling part of the mainstream, and being "invisible." Many people with disabilities, on the other hand, are prevented from gaining full access to the world at large, are constantly made aware of their "disabled" status, and feel excluded from the mainstream. Compare and contrast what the terms "able" and "disabled" signify. What are some structural, cultural, and economic barriers that prevent disabled people from being present in the mainstream and how have some of these barriers been surmounted in the past (Charlton, 1998; Shapiro, 1993)?

## 5. Teach the history of people with disabilities.

This history can be explicitly taught in a unit, woven throughout an interdisciplinary curriculum, or offered as a class project. People with disabilities have always existed, yet the understanding of various conditions and impairments have differed within various cultures and changed over time (Stiker, 1999). People of short stature were accorded special powers in ancient Egypt. The deaf, unable to hear "the word of the Lord," were denied entrance to heaven in the Middle Ages. Those developmentally and physically impaired were interred in Nazi death camps. People with disabilities also organized the Disability Rights movement (Fleischer & Zames, 2001). This history is a distinct, fascinating, and complex account of human diversity that has yet to be fully explored.

# 6. Analyze stereotypes of "good guys" and "bad guys."

Have students draw representations of their understanding of how incarnations of good and bad look. Many will portray "bad" as having a physical disability--a hunched back, a hook, wooden leg, an eye-patch, an "ugly" face, or an animal-like monstrous appearance. Indeed, classic "bad guys" including pirates and witches are often generated. In contrast, "good" is often portrayed as individuals with long flowing hair and a smiling face, something akin to a stereotypic angel. Challenge the notion of evil being represented by specific physical

characteristics. What do these images tell us about our society's values? What might be some analogies with racism? Which people benefit from such imagery, and which are disadvantaged? How can we create characters beyond two-dimensional representations?

## 7. Critique representations of disability in film.

The overwhelming majority of films portray people with disabilities in inaccurate and damaging ways, reinforcing stereotypes (Darke, 1998; Safran, 1998a; Safran, 1998b). After learning about the real life experiences of blind people, watch *Scent of A Woman*. While undeniably entertaining, Al Pacino's Oscar winning performance of a bitter, lonely, self-loathing, socially-rejected, suicidal man who feels faces to "see" a person (a myth) and has an incredible sense of smell (another myth), conforms to misunderstandings of blindness. Discuss what is problematic about such pervasive representations. More importantly, clarify the everyday experience of blindness as "normal" for some people.

## 8. Use progressive representations of disability in film.

Many portrayals of people with disabilities end in death. Oscar winners of 2005, *Million Dollar Baby* and *The Sea Inside* actually stress that suicide is preferable to living with a disability. Contrast widespread negative messages with portrayals of positive portrayals of disability in *The Station Agent*, in which a person of short stature leads a "normal" life. In *Finding Nemo*, where being of short stature or having a "gimpy" body part is viewed as one aspect of a person. *Shrek I* and *Shrek II* in which "monstrous" physical attributes are seen by most characters as simply another way of being.

# 9. Reinterpret representations of disability in children's literature.

Much of the children's literature has been criticized for inaccurately representing life with a disability, while invoking emotions of pity and/or admiration in readers (Ayala, 1999; Solis, 2004). This can be countered by teaching the broad topic of difference in texts such as *Chrysanthemum, Charlotte's Web, Rudolph-the-Red-Nosed-Reindeer*, and *The Secret Garden*. How is the character different? How is she or he perceived by others? What are the consequences? How does she or he, in turn, respond? What can we appreciate about the idea of difference from knowing a specific character? Culling from multicultural studies, several scholars in education have designed criteria that are useful in evaluating children's stories for accuracy of disability representation (see Blaska, 2004; Worotynec, 2004; Ziegler, 1980). Furthermore, inclusive education has pushed the envelope in terms of directly incorporating the teaching of disability in the curriculum (see *Nine Ways to Evaluate Children's Books that Address Disability as Part of Diversity* at http://circleofinclusion.org).

## 10. Use progressive representations of disability in literature.

In Dickens's *A Christmas Carol* (1843/1986), Tiny Tim is the quintessential helpless, sickly, passive, pitiable disabled child. To counter such "classic" portraits, use contemporary books that depict being disabled as actually being able to do many things, and unable to do some things, such as *Friends in the Park* (Bunnet, 1992), *Lester's Dog* (Hesse, 1993), *The Fly Who Couldn't Fly* (Lozoff, 2002), *Mandy Sue's Day* (Karim, 1994), and the autobiographical *Trouble With School: A Family Story About Learning Disabilities* (Dunn & Dunn, 1993), thereby providing more accurate and realistic representations of disability (Blaska & Lynch, 1998). In

addition, read-alouds can be a great venue for facilitating discussions about different disabilities (Richardson & Boyle, 1998).

## 11. Use literature designed to help students understand themselves.

There is a growing body of literature aimed at helping students understand the ways in which their own bodies and minds work. *All Kind of Minds* (Levine, 1993) is a book that describes fictional students who have difficulties with attention, organization, memory, behaviors, receptive and expressive use of language, and features ways in which they address their areas of need. In addition, *Keeping Ahead in School* (Levine, 1990) explains to children and adolescents the ways in which everyone's mind works and the way humans manage the executive functions of our brains in negotiating the academic and social demands of school.

## 12. Critique representations of disability in classic literature.

Most "classic" texts taught in schools are populated with disabled characters such as Shakespeare's *Richard III* (1600/2004), Melville's *Moby Dick* (1851/2001), Steinbeck's *Of Mice and Men* (1937/1986), Tennessee Williams's *The Glass Menagerie* (1945/1999), Toni Morrison's *Sula* (1973), and August Wilson's *Fences* (1986). On closer examination, disability often *defines* the character and usually acts as a plot device to further the action or advance a theme (Mitchell & Snyder, 2000). Examples include a hunchback to represent evil and inevitable doom, a slow mind that does not comprehend the physical strength of its accompanying body, a wooden leg that fuels a vengeful drive, a limp that defines a closed world of narrow opportunities for all of the family, a mentally-ill brother whose war service signifies financial reparation, and a one-legged woman who oversees an unconventional household and all it represents. Predictably, the majority of characters either die or remain at the margins of society. Students can discuss the real experience of disabled people versus those portrayed, rewrite alternative endings, or create portrayals in which a disability is part of a character without being the defining characteristic that triggers their demise.

## 13. Use documentary video and films.

Many excellent documentaries exist that reveal the personal perspectives of people with disabilities and how their own understanding of impairment is often quite different than that of non-disabled people. Three examples are: The Cosby Foundation's *Ennis's Story* (Seftel, 2000), a compilation of celebrities, distinguished professionals, and actual schoolchildren who describe their "learning differences"; Jonathan Mooney's *What The Silenced Say* (Golden, 2001), describing schooling from the point of view of a struggling reader; and Mel Levine's *Misunderstood Minds* (Sicker, 2002), a glimpse into how children with different learning styles learn to accept themselves and negotiate education systems that are not always accommodating of difference. Other informative documentaries such as *Educating Peter* (Wurtzburg, 1992) and *Sound and Fury* (Weisberg, 2000) chronicle the journeys through school of students with autism and deafness respectively. In addition, *On a Roll* (Caputo, 2005) and *Emmanuel's Gift* (Lax & Stern, 2004) reveal out of school experiences for an African-American coach and a Ghanian athlete respectively, both powerful portrayals of individuals at the interstices of being disabled and a person of color.

## 14. Disability as way of understanding the world.

There are many excellent first person narratives from the position of a person with a disability. Most of these accounts do not posit disability as an overwhelmingly negative trait, but rather as a way to understand the world albeit differently than others. Thus, having a label like ADD or ADHD is subsequently seen as a way to multi-task, to be creative, and not be confined by the rules of society (Mooney & Coles, 2000; O'Connor, 2001). In addition, to be learning disabled is to understand how society is currently configured to privilege some ways of learning and knowing over others (Piziali, 2001). Having guest speakers with disabilities who are students and adults can be extremely informative. Educators can ask how written or oral first person accounts of disability differ from information gleaned from books, conveyed in films and television, and presented by "experts." Which information is the most accurate and valuable?

## 15. Use the arts.

By focusing on the "human" within the Humanities, we can see how disability has informed the creative process. Andrew Wyeth's *Christina's World* portrays his next door neighbor who is unable to walk, yet he deliberately positioned her as openly facing a wide-open space and not inhibited by expectations of confinement (P. Mayer, personal communication, March 2004). Disabled painters include: Frida Kahlo and her deeply personalized works that depict the effect of a road accident on her body and mind, yet have produced arguably the most famous female painter in the world; Matisse and Monet, whose later works in particular were in part because of limitations on their eye-sight (Linton, 2004); Van Gogh and his canvases that portray an unparalleled intensity, vivid and alive, created throughout an emotionally turbulent life; and Toulouse Lautrec, with his ability to capture the "underground life" of Paris. In US in the late twentieth century, "outsider art" became accepted as a genre for artists without formal training, many of whom are labeled "mentally challenged" and have spent part of their lives institutionalized. Students can discuss the influence of bodily difference on the creative process, and the role of disability in the lives of various artists.

## 16. Research projects.

Students can research the broad and multifaceted theme of disability in many ways. For example, once introduced to the ethics of doing research, they can informally interview members of the immediate family, neighbors, and family friends who have a disability to see how people with disabilities come to view themselves in general. Do they consider themselves as disabled or different? Does that change according to context? Older students can explore an aspect of history, such as the rejection of disabled people at Ellis Island, the growth of deaf culture, or the Individuals with Disabilities Education Act (originally P.L. 94-142) that legally provided a *right* to education for children with disabilities.

## 17. Analysis of cartoons.

From short-sighted Mr. Magoo to inarticulate Elmer Fudd, from developmentally delayed Dopey the Dwarf to stuttering Porky Pig, whether in animal form or human, disability is usually portrayed as something to be ridiculed. Students can discuss and critique the connection between disability and comedy and how laughing at others because of their difference is essentially discriminatory in nature and can have hurtful consequences. With older students, contemporary television shows such as South Park are ripe for scrutiny as everything and everybody is ridiculed with equitable zeal. However, the characters of Timmy and

"handicapable" Jimmy thwart easy analysis, and offer multiple opportunities to discuss the complexities of disability both in and out of school (Reid-Hresko & Reid, 2005).

## 18. Disability rights movement as part of social studies.

Inspired by the demands of African-Americans, women, and gays for equality in all aspects of society, the Disability Rights Movement has been instrumental in organizing political power from a grass roots level. Changes in access to transportation, education, employment, community integration, health care, housing, and technology have greatly improved the lives of many people with disabilities. At the forefront of these changes were disabled activists who staged protests, sit-ins, and argued vociferously to speak for themselves and be heard. Students can contemplate in what ways the disability rights movement is similar to and different from other movements. What have been the breadth and limitations of this movement?

## 19. Alternatives to disability-related simulations.

"Disability Awareness Days," while well intended, are at best misleading, and at worst, inappropriately perceived as "fun" activities for people without disabilities. To understand what it is like to have a disability, ask students *not to go to* places that are inaccessible. Ask people who have disabilities how they use accommodations and modifications. Look at devices such as different types of light switches, door handles, showers, cars, etc. that focus on how ordinary people with disabilities maneuver throughout their day. Discuss the concept of universal design, the creation of buildings from their very inception to accommodate people with all different types of needs.

## 20. Use disability studies as a resource.

Over the last twenty-five years, there has been a growth in disability studies as an interdisciplinary field. Recently, there has been a surge in interest in disability studies and education (Gabel, 2005). Disability studies places the voices of people with disabilities at the center of theory, research, and practice. Thus, perspectives of disability are richer, positive, and far more diverse than is often found in representations within professional literature and the media at large. Ideas from disability studies have been used to reframe disability as part of the natural human experience in the work of several teacher-educators (Connor, 2004; Gabel, 2004; Ferguson, 2001; Ware, 2001).

While we recognize that much of what we have suggested are valuable ideas, we would also like to call attention to the intersectional nature of disability. By that, we mean the experience of disability does not stand alone in a vacuum, but rather intersects with other markers of identity including, but not limited to gender, race, ethnicity, nationality, sexual orientation, and age. It is clear from our discussion that the overwhelming majority of examples tend toward middle-class, European-American males. Indeed we agree with Bell (2006) who has critiqued disability studies for not sufficiently acknowledging the intersectional experiences of people with disabilities. In addition, we believe all of us in this field should strive toward furthering such approaches, thereby enabling us to enrich our understanding the phenomenon of disability.

In closing, these twenty options are classroom-based strategies that continue to actively work against disability as a negative phenomenon. Instead, they serve to challenge stereotypes that cast individuals with disabilities as one-dimensional characters in restrictive roles, either super-passive or superhuman, pitiable, stigmatized, and perpetual objects of charity. By using

these strategies, longstanding depictions of people with disabilities are challenged, reframed, and replaced by understandings of disability as simply part of human diversity.

- **David J. Connor** is an Associate Professor in the Learning Disabilities Masters Degree Program at Hunter College, City University of New York. He has recently co-authored a book with Beth Ferri, *Reading Resistance: Discourses of Exclusion in the Desegregation and Inclusion Debates* (Peter Lang) and is working on another book titled "Urban Narratives: Life at the Intersections of Learning Disability, Race and Social Class," featuring first person narratives of life at the intersections of learning disability, race, and social class. His research interests include learning disabilities and inclusive education.
- **Dr. Lynne Bejoian** is an Associate Professor in the Inclusive Education and Disability Studies Masters Degree Programs at Teachers College, Columbia University. She has recently co-edited an issue of *Equity & Excellence in Education*, called "Narrating Disability: Pedagogical Imperatives" (June 2006). Her research interests include spirituality and disability, disability in the media, and inclusive education.

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# Disablism Reflected in Law and Policy: The Social Construction and Perpetuation of Prejudice

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Abstract: There are widespread historical and cultural analyses of the problems associated with racism, sexism, classism, and other types of prejudice; however, there is a paucity on disablism. As with other prejudices, an examination of the origins and perpetuation of disablism is controversial because it is cloaked in narrow legal and policy analyses of the historical and cultural documentation on the notion of disability. There has been little systematic research on disablism and typically it has been misrepresented as a health, economic, technical, or safety issue rather than prejudice. In the United States, the Americans with Disabilities Act of 1990 (ADA) was signed into law with the assumption that it would provide equal accommodations for disabled people. In this paper, we examine the institutions of education and the workplace to analyze how "equal accommodations" under such policies pose some serious and problematic political processes and consequences in shaping disability rights. Our analysis suggests that from an international perspective most disability policies remain rooted in a narrow medical model, despite evidence of attempts to construct politics of diversity and self definition.

**Key Words**: diversity, disablism, politics

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#### Introduction

On July 26, 1990, President George H.W. Bush signed into law the Americans with Disabilities Act of 1990 (ADA), which was touted as the most progressive piece of American legislation since the Civil Rights Act of 1964. Although the ADA is often hailed as a revolutionary landmark, the emancipation proclamation for the American disability community, the foundation for this law originated from a problematic process of shaping disability identity and the perception of what it means to be disabled.

Although there is little discourse on disablism, the Greater London Authority Act of 1999 (GLA) on Disability formally accepted disablism as a social phenomenon and a form of societal oppression towards disability similar to racism or sexism. Along with their recognition of laws such as the ADA, this discourse from a British authority is among the few authorities that

recognize the importance of eradicating such prejudice. Increasingly, disabled individuals resonate to the problems of disablism and some scholars are trying to eradicate the rarely subtle, deep negative impact of such prejudice.

Disablism promotes the concept that disabled individuals are inferior to others, which not only unconsciously shapes the identities of disabled individuals, but also permeates the apparatus of existing political disability processes (Gillinson, Miller, & Parker, 2004). The concept of disablism increasingly is useful in international research because it helps us examine its connection with the roots of other forms of prejudice such as racism, sexism, and classism. Moreover, the roots of this specific prejudice require more systematic analyses and explications, otherwise, public policy solutions probably will continue to be partial or subject to numerous forms of backlash. Human rights groups, such as the European Union's Human Rights and Democratisation Policy, continue to grapple with such problems (UN Commission on Human Rights (2004); Human Rights of People with Disabilities, 2004).

In the recent past, people with disabilities, also termed "disabled people" in popular culture, were defined and "treated" for the most part on the basis of their physiological condition. They were usually identified as not having the ability to function normally and efficiently in education and the workplace. As the ADA of 1990 began to be implemented, there was initially a small shift from a physiological perception to a more cultural view of being disabled. This law, and related ones in the U.S., however, continue to define disability from a medical model in shaping the prerequisites of being disabled (Lauderdale, 2003). Additionally, the ADA "reproduces the medical definition by defining it as an inability to perform a 'normal' life activity" (Donoghue, 2003, p. 202-203). The ADA, as a political process, was created for the purpose of measuring basic accommodations to ensure "equal opportunity" in our society. This law also confirmed old notions of disability and related accommodations to shape the identity of what it means to be disabled. The ADA became embedded in our social fabric by shaping and normalizing specific identities, attitudes, opinions, and behaviors.

Although the ADA was an important legal victory for the disabled community, especially in terms of creating more awareness of the various issues of disability, the effect of the ADA has been in many ways, to perpetuate a medical model that continues to neglect the complex sociocultural aspects of disability (Donoghue, 2003; Jolly, 2003). Perhaps the clearest replication of the medical model can be seen in states' continued adherence to policies that promote institutional over community-based services for disabled individuals. These policies reenforce disablism by isolating those with disabilities from society at large and forcing dependence on the state for even basic services (O'Brien, 2004).

## Semantics and Political Processes of Disablism

Typically, disabled people are defined and treated as a homogenous group by most societies, which usually leads to critical problems with legislation and the implementation of laws and policies (Martin, 2002). The ADA, for example, originates from a calculated analytical process called *rationalized* legal reasoning that results in "the lack of required, legally, correct rules, methodologies, or results...[and] is in part of a function of the limits of language and interpretation which are subjective" (Kairys, 1998, p. 5). Scotch (2001) explains how Section 504 of the Rehabilitation Act of 1974 formed a foundation for its successor legislation, the ADA, and developed largely out of a process of legislative and political maneuvering. Its passage primarily was the result of intense political negotiation rather than activism by advocates for the

disabled. United States policy has consistently attempted to rationalize the ADA "objectively," without respect to diversity.

Despite the disabled-positive rhetoric surrounding the legislation (GLA) in London, the Disability Discrimination Act of 1995 (DDA) in the United Kingdom shares the same neglect of diversity as the ADA in the U.S. by ignoring the diverse gifts of ostensibly disabled people and trying to normalize differences in the home, at school, and the workplace. Stevens (2002, p. 782) notes that "progressive" civil-rights laws " will not necessarily solve social problems" and suggests that the DDA is subject to similar problems as the ADA, including the failure of British policy to eradicate "psychological barriers." Critics of the DDA argue, for example, that not enough conditions that contribute to disability are covered under the auspices of the Act, enabling employers to avoid liability for workplace-related disabilities and providing few outlets for coverage for the mentally ill.

Further, and perhaps more importantly, both the DDA and the ADA treat the disabled individual as the "cause" of disablement rather than society as a whole (Barnes, 1996). For example, the ADA and the DDA do not separate disability from the individual. Legal definitions proffered by these acts focus on the "functional attributes" of disabled people rather than acknowledging the fact that stigma and societal attitudes are the major reasons for discrimination against the disabled in the workplace and otherwise (Hahn, 2000). The conception of an individual as "disabled" becomes the fault of the individual rather than the result of a societal structure that fails to recognize diversity.

The origins of classifying and examining disability in education and the workplace have been conducted through an anthrocentric and narrow scientific examination. Education and workplace definitions neglect diverse disabled cultures and homogenize a disability identity where values, heritage, and history are simplified and normalized. In *The Life of the Law*, Nader (2002) refers to anthrocentric notions of the law as the culturally-biased approach of gathering information by not incorporating diversity and ignoring historical conflicts. The definition of disability and the formal apparatus defining and accommodating disabled people is perceived as a "social problem made by trained experts who may depart quite substantially from public perceptions of social problems" (Lauderdale, 2003, p.19). This conundrum further ignores the full socio-cultural implications of disability (Jakubowicz & Meekosha, 2002).

The ADA allows bureaucratic decision-making processes to be created under an ambiguous hierarchal structure of power regulated by rational formal law, in the guise of a "progressive" reform. Determining the varied impacts of the ADA is very difficult. Avoke (2002) suggests, for example, that the absence of legislative and policy frameworks for disability issues in many economically poor countries leads to greater stigmatization (See Avoke, 2002, p. 772 on Ghana). Yet, public policy historically has neglected the diverse cultural identities of disabled people in its attempt to homogenize disability and make policy such as the ADA a calculated process through narrow legal reasoning.

Under the ADA, an individual who has a physical or mental impairment that "substantially limits" one or more of his or her "major life activities" is considered to be "disabled" (42 U.S.C. 12102). Thus, to receive social services pursuant to the ADA, individuals must identify some form of disability. However, many disabled individuals, while in need of the services and protections provided by the ADA, may not themselves identify as "disabled" *per se*. For example, many deaf individuals may identify instead with being part of a deaf "culture" in which being hearing impaired is not perceived as a handicap, but rather a linguistic difference (Barnartt & Scotch, 2002; Lane, 1999).

Thus, the ADA coerces disabled people to be defined and treated as a homogenous group without regard to how they may identify themselves. This is especially true because in order to receive services guaranteed by the ADA, the individual has to acknowledge and accept having a disability regardless of their viewpoint of being disabled. Identity politics of diversity criticize the risky process of law in creating a cauldron in which "inequalities of class, gender, race, age, and disability are brewed into a lethal cocktail" (Humphrey, 1999, p. 175). Similarly, Nader (2000) explains that the "harmonious" process of the law to settle conflicts with norms such as "equal opportunity" and "full accommodations" as "legal values" neglect the cultural identity of being disabled. Narrow attempts to create a "harmonious" law based on unity and conformity often produce problematic definitions that lead to disablism.

We suggest that diversity is a more accurate description of disabled people. They are not disabled per se, but rather diverse. Diversity here reflects (a) the significant differences in the ranges and depths of individuals who are defined as having some type of disability, (b) their "place," which includes their socioeconomic status, gender, ethnicity or race, age, and power, and (c) their varying responses to the label of disability, which often depends on interpersonal and structural relations of power.

## The Impact of Policies on Education and the Workplace

In education and the workplace, policies such as the ADA supposedly address different levels and forms of disability ranging from deafness, blindness, cognitive disorders, multiple sclerosis, mental retardation, and many other disabilities. The notion is that everyone with these disabilities will receive equal opportunities. Furthermore, such policies attempt to homogenize all disabled people by mainstreaming them into the sea of "normally functional" persons with "equal opportunities," yet, the laws inadvertently reinforce the "negative attitudes, limited physical access, limited access to communication and/or economical, political, or social resources, and to the rights and privileges of a social group" (Gilson & DePoy, 2004, p.17). Donoghue (2003) reaffirms this problem by explaining how the ADA has marginalized diversity by creating a narrow definition of what it means to be disabled in education and in employment.

In the American system of education, the Individuals with Disabilities Education Act (IDEA) outlines an approach where disabled students historically have been measured, compared, classified, and moved into "special" classrooms away from the general education system. It is as if the exclusive placement of the student in the special classroom is an organizational pathology diagnosed by examining the degree of disability (see, e.g., Winzer, 1993). This social exclusion often results in stigma (see Jahnukainen, 2005, for a comparative analysis).

The student is measured by linguistic and cognitive strengths and weakness formulated from a medical model *ostensibly* to assess the student's learning abilities. In reality, the student's educational assessment is not a measure of what the student is capable of accomplishing, but rather what she or he is incapable of accomplishing by "characteriz[ing] the difference in great biological detail" (Lane, 1999, p. 24) with the neglect of any cultural dimension.

Although the IDEA, passed in 1975, amended in 1997 and updated in 2004, requires a detailed explanation for excluding children from the general education classroom, application of the standards set for inclusion in the act is often uneven. Cole, Waldron, and Majd (2004) note, for example, that poor inclusive programs that do not meet students' needs are frequently

implemented (in Baines, et al., 1994; Shanker, 1994-1995; Vaughn & Shumm, 1995). Students often encounter even more difficult problems in educational systems in countries with fewer economic resources than in the United States (see, e.g., Balias and Kiprianos, 2005, regarding Greece).

In the workplace and related economic sectors, the disabled worker is also measured, compared, and classified by their capability to perform efficiently against their counterparts in the workplace. Both the United States and the United Kingdom created policies to spearhead equal opportunity in the workplace, but instead affirmed the government's economic policy by only partially attempting to make the workplace equally accessible (Jolly, 2003). The field of employment, using questionable rational and calculable processes to provide "equal opportunity" has been able to exploit and control the workforce through linking physiological ability with being a wageworker. The U.S. Census Bureau (2001) reports that:

"The proportion of individuals 25 to 64 years old with an annual personal income less than \$20,000 was 80.2 percent for those with a severe disability compared with 43.7 percent for those with no disability. When the income measure was household income, 41.8 percent of those with a severe disability, and 13.9 percent of those with no disability, lived in a household with an annual income below \$20,000" (p. 70).

It is not surprising, then, that the employment rate and median annual earnings for individuals 25 to 64 years old by overall disability status and by specific disability categories are also strikingly different. According to the same Household Economic Study by the Census Bureau, individuals with a severe disability had an employment rate of 31.4 percent and median earnings of \$13,272, compared with 82.0 percent and \$20,457 for those with a non-severe disability, and 84.4 percent and \$23,654 to those with no disability.

Congress specifically mandated major goals when enacting the ADA such as ensuring "equal opportunity" in the workplace by claiming to eliminate the arbitrary barriers faced by disabled people. Yet, the disabled employee continues to be classified through their inability to function as a normal wage worker as part of a systematic division of labor. When policies such as the ADA present the disability worker with an ontological "equal opportunity" ideology claiming that he or she will be guaranteed equal chances in the workplace, in reality these laws reproduce and solidify the periphery between realistic solutions and symbolic arbitrary resolutions. For example, as Barnes (1996) notes of the "reasonable accommodations" mandate under the Disability Discrimination Act (DDA) in the United Kingdom, discrimination remains justifiable in those circumstances where the accommodations that employers must make to accommodate disabled workers are deemed to be "unreasonable." In the U.S., the courts frequently have been unwilling to grant assistance with transportation costs to employees as part of a "reasonable accommodation" under the ADA, although lack of access to transportation is often a major barrier to employment for the disabled (Hahn, 2000).

The increasingly complex division of labor leads to increased interdependency of economics and power, an interdependence that is necessary to develop a stable, predictable, and reliable strategy of welfare and government. The influence of economics on disability policy is crucial in explaining critical interpretations and problems of disablism in the workplace (Russell, 2002). Jolly (2003) suggests that economic justice is embedded in identity and culture where:

"The economic and social organization of modern societies are formed through historical

and shifting power relations, which disable, render problematic or prevent those with impairments from taking part in activities such as mainstream education, paid work...access to public transport, public buildings and access to information" (p. 511).

#### Centralization of Power

The portrayal of disability in the ADA becomes important when explaining numerous interpretations of the politics of disability in the workplace and in schools, especially from an international perspective. An underlying social structure prevents many public policies from producing significant impacts. Some of the classic work by Max Weber, based on his comparative research, can be useful in examining these impacts. Changes in the centralization of power, for example, are critical to different bureaucratic organizations (Weber, 1968; Inverarity et al., 1983; Swedberg, 2000; Oliverio & Lauderdale, 2005). As a society becomes more complex, typically there is an increased centralization of power in bureaucratic organizations guided by the notion of efficiency, reliability, legitimacy of authority, calculability, regulated tasks, and rules for predictability. The bureaucratic organization, then, increasingly has become a calculated and rational set of activities regulated by a multitude of hierarchal agencies (Weber, 1968).

These organizational bureaucracies emerged with authority from what Weber calls a "formal rational" framework of reliable, disciplined, rationalized, specialized, and methodological calculations in education and employment (Inverarity, Lauderdale, & Feld 1983; Swedberg, 2000). This process has resulted in the neglect of diverse disabled cultures, which homogenize the identity of disability as a collective where values, heritage, and history are normalized. Policies such as the ADA allow the bureaucratic decision-making process to be created under an ambiguous, hierarchal structure of power, regulated by rational, formal, explicit law as an ostensible progressive reform. The process contributes to the avoidance of the full sociocultural implications of disability.

In education, students undergo a series of formal "scientific" assessments where they are evaluated, classified, and compared based on the severity and the nature of their disability. Additionally, students "bear the character of abstract norms, which, at least in principle are formed and distinguished from one another by a rigorously formal and rational logical interpretation of meaning" (Weber, 1968, p.789). They are classified through linguistic and cognitive comparisons with their non-disabled counterparts, using blind empiricism as a tool to provide accommodations by primarily using only empirical correlations. Thus, policies increasingly operate through a formal rationalized process that creates partial accommodations for disabled people; by doing so, they neglect essential sociocultural factors. The educational system, through most policies, homogenizes all of the diverse heritages, histories, languages, and modalities of each disabled student into a monolithic idea that each individual will receive an equal education. The marginalization of the diversity of disabled students provides the educational system with predictable, consistent, and rationalized methodological calculations of processes at the expense of diversity.

In the workplace, disabled employees are classified through their inability to function as normal wage workers, without consideration of the social barriers involved in the workplace. Disability policy provides the worker with:

"[An] arbitrary combination of professional assessment, paternalistic welfare, and compulsory employment...categorization as capable or incapable to work; deserving or undeserving. They are experiencing increasing insecurity, pressure to conform, a heightened sense of powerlessness and of being under the attack" (Beresford & Holden, 2000, p. 983).

Beresford and Holden also point out from a global perspective that the categorization and classification of disabled people illustrates the increased specialization of social policy in constructing the role of the disabled person. These bureaucratic policy-making decisions allow the development of a stable, predictable, and reliable strategy of welfare and government in the name of disability policy (Jolly, 2003). This political process also forms a hierarchal structure, bureaucratic discipline, and centralization of power because of increasingly complex labor in the workplace and educational institutions (Weber, 1968). It is a crucial Weberian process that provides an interpretation of what it means to be disabled and how to accommodate disabled people in both the workplace and in education.

## A Brief Examination of Normalizing Judgment

The impact of many historical definitions and reactions to diverse people lingers. The emergence of eugenics, for example, in the late nineteenth and early twentieth centuries in most countries, legitimated the institutionalized confinement and explicit biological stigmatization of a myriad of people. They were labeled with negative biological terms as a method to isolate them from the general population. They were confined in homes, asylums, schools, and hospitals. The solution to difference was "segregation of all the 'defective' classes, the 'great neuropathic family,' as one expert called them, 'the insane, the epileptics, feeble-minded, the neurotic tramps, criminals, paupers, blind, deaf, and consumptive" (Longmore, 2003, p. 46). The eugenics movement emerged as popular ideology and by 1930 more than half the States in the United States adopted sterilization laws. Disabled people were involuntarily sterilized in a pseudo-scientific effort to prevent the births of disabled offspring. There were systematic attempts to abolish the disability community because it was perceived as a social and economic burden to society, which prompted most policy-makers to stigmatize and isolate people with so-called disabilities. Social organization, through stigmatization and institutionalization, shaped and solidified the psychological/medical perspective of disability.

The exclusion of sociocultural factors in diverse subjects is legitimized and regulated by medical definitions. Intervention then becomes social control that "seeks to limit, modify, regulate, isolate, or eliminate deviant behavior with medical means" (Conrad & Schneider, 1992, p. 29). Political processes further homogenize the construction of disability as the medical model becomes the dominant paradigm, in part, because of the benefits of "speaking" in medical and health terms (Lauderdale, 2003). These politicalized scientific processes in various types of governmental agencies and bureaucratic organizations contribute to the creation of disabled people as objective subjects (Tremain, 2005).

Over thirty years ago, Michel Foucault (1975), in *Discipline and Punish*, explained how individuals are created through the examination of docile bodies as a scientific construct and through techniques of normalizing judgment. The confinement of docile bodies, which excludes and denies access to power and privilege, includes not simply a focus upon the body, but also the scientific power to describe the physical body as a target for the exercise of power. Thus, social

constructions of disabled students and workers are broken down into a series of formal "scientific" processes where they are evaluated, classified, compared, and examined based on the severity and the nature of their disability.

This examination makes it possible, through the apparatus of writing, to document "the constitution of the individual as a describable, analyzable object...to maintain him in his individual features, in his particular evolution, in his own aptitudes or abilities, under the gaze of a permanent corpus of knowledge" (Foucault, 1995, p. 190; Oliverio & Lauderdale, 2005). Thus, the examination of bodies is a form of explicit power through the "corpus of knowledge" and it is the regulation of knowledge that reinforces the political outcome of this particular power (Tremain, 2005). Each disabled individual is a case that may be measured, classified, categorized, homogenized and normalized. A criterion, for example, is used to measure difference in people creating a facade of diversity. In reality, the one criterion that is measured makes real the homogeneity perspective under which so-called disabled people are viewed, judged and set apart (Brown, 2003). The power of normalization through examination "imposes homogeneity; but it [also] individualizes by making it possible to measure gaps, to determine levels, to fix specialties, and to render the differences useful by fitting them one to another" (Foucault 1995, p.184).

In education and in the workplace, a disabled person is examined as a case that can become a commodity, which can be classified, repaired, and recorded. Historically, governmental agencies and bureaucratic organizations exercise their power and knowledge via ostensible scientific processes by using medical terminology, symptoms, "equal opportunity" solutions, and anti-discrimination rhetoric. Empirical examination by these agencies as "experts" further affirms their scientific control. The classification and normalization of disabled people becomes a necessity within intellectual, social, and economic frameworks (Foucault, 1995).

The biological and cultural identity of the diverse disabled individual is pulled apart. The body as a social and historical construct is oblivious and docile. By using disciplinary techniques of biology as the powerful, scientific language of normalizing judgment and examining the body, disability becomes devoid of history and culture (Lane, 1999). This process makes it efficient, predictable, and rational for public policy to be presented in its idealized form, which would provide "equal opportunity" in education and the workplace, yet, without appropriate sociocultural consideration. The process is partially a result of trying to formally employ the legal system, namely, in the workplace and education, while attempting to use "accurate" empirical and scientific conclusions. In addition, most policy is being explicated as a legal concept as if people are universal, homogenous, and normalized without respect to diversity.

## Conclusion

The impact of science and law on public policy throughout this paper is understood as, in part, a political process that produces problematic consequences for the disabled person. We focus here upon only two examples from the institutions of education and the workplace. The political process of what it means to be disabled and how to accommodate people by laws such as the ADA can be understood as an ideological system of normalization. Social and political relations develop classifications for intellectual, social, and pathological functioning of disability. Thus, this process allows the ontological creation of disability and its problematic

identity in education and in the workplace.

Policy has relied on an anthrocentric Western framework of law to define disability and its place in society. By using a medical approach to rationalize the legality of accommodating disabled people in society, public policy centralizes disability through historical and cultural rejection. Disability, therefore, needs to be addressed globally, historically, and culturally if we want to understand and alter the "dynamics and change in the government of disability and in the process of economics and power" (Jolly, 2003, p. 520). We need to know how power, knowledge, and economics are historically instrumental in politics, and how they shape disablism in our society, namely, in education and employment. Policies can be understood heuristically as a doctrine, a form of law, implemented to control the "disabled "society through the creation of scientific constructs. These constructs are used to create and examine docile bodies and to normalize judgments that unfortunately prevent disabled people from receiving full accommodations and equal opportunity in education and the workplace. Diversity is ignored or becomes suppressed as deviant (Brown, 2003; Lauderdale, 2003).

## **Future Study**

Policy for persons with disabilities remains fragmented. Millions of dollars have been spent in recent years on social welfare, vocational rehabilitation, and employment programs that often have led to the marginalization of diverse people (Thomas & Lauderdale, 1988; Lauderdale, 2003; Switzer, 2003). The disability movement has fought to regain autonomy of sociocultural values by attempting to eliminate the medical model and reveal why the means to an end are deeply important. Even something that on first glance appears simple, such as a charity telethon to raise funds for "disabled" people, for example, can segregate them and label them as deviant (Brown, 2003). Future research can explore why diversity is a more accurate description of disabled people than simply labeling them as a heterogeneous group (see Jakubowicz and Meekosha, 2002, for various definitions and labels in Australia and Western Europe). Diversity would include, at least, the significant differences in the ranges and depths of individuals who are defined as having some type of disability, and their place in society, which includes their socioeconomic status, gender, ethnicity, race and age.

Different forms of science are accelerating faster than ethical debate and policymaking. As long as pseudo-science continues to be a dominant part of the politics of disability, there will be more deviance designations in bureaucratic organizations to contain, regulate, and (re)shape disablism with the continuing neglect of diversity. The application of pseudo-science to measure and normalize, via disablism, will continue to destabilize the much needed self-determination of the international disability community. An important step now is to promote research that explains why disability policy requires a sociocultural model with the inclusion of diversity.

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# Raising Disability Awareness and Self-Efficacy of One-Stop Workforce Center Staff Serving Job Seekers with Disabilities

Richard Johnson, Daryl Mellard, & Thomas Krieshok University of Kansas **Abstract:** Under the Workforce Investment Act of 1998 (WIA) access to employment services for all job seekers, including those with disabilities, is available partly through a system of One-Stop Workforce Centers (Storen & Dixon, 1999; U.S. Department of Labor, 2001). However, early studies of WIA implementation found that One-Stops had limited outreach to and lacked accessibility for people with disabilities. This article describes a training program designed to raise disability awareness and self-efficacy of One-Stop staff serving people with disabilities, and to contribute to a unified culture of sensitivity toward, and an ability to work with, job seekers with disabilities.

## **Key Words:** disability awareness, internet training, workforce centers

Prior to the Workforce Investment Act of 1998 (WIA) implementation, many job seekers with disabilities received services from multiple government agencies to meet their employment needs (Timmons & Fesko, 2002; Timmons, Schuster, Hamner, & Bose, 2002). Others, who might have benefited from multiple agency services, did not access those services because they found navigating differing agency requirements too difficult (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). Thus, the U.S. Congress enacted WIA, intending to create seamless access to employment services for all job seekers, including those with disabilities, in part through a system of One-Stop Workforce Centers (Storen & Dixon, 1999; U.S. Department of Labor, 2001).

Although Vocational Rehabilitation (VR) agencies, which provide for the career development, skills training, and employment needs of job seekers with disabilities, are mandated partners in WIA's One-Stop system, many policy analysts and disability advocates expressed concerns that people with disabilities might not receive the specialized services they need in a system that is integrated with the general population of job seekers (e.g., Cohen, Timmons & Fesko, 2005; Consortium for Citizens with Disabilities, 2003; Holcomb & Barnow, 2004; National Council on Disability, 2002). Concerns ranged from the possibility that One-Stop staff may attempt to offer basic services without making appropriate accommodations for individual with disabilities to the possibility that staff might automatically refer job seekers with disabilities to VR for intensive services without offering any basic services at all. These concerns, in fact, have some degree of merit.

Early studies of WIA implementation (Funaro & Dixon, 2002; Timmons, Schuster, Hamner, & Bose, 2002) found that One-Stops had limited outreach to and lacked accessibility for people with disabilities. Furthermore, these evaluation studies noted that One-Stops had no performance measures related to disability, had issues with agency culture from the blending of multiple programs, and had a lack of coordination between services for people with disabilities. More recent studies of One-Stop services for individuals with disabilities (Cohen, Timmons, & Fesko, 2005; Hall & Parker, 2005; Holcomb & Barnow, 2004; U.S. Government Accounting Office, 2004), although noting improvements in physical accessibility, found ambiguity and conflict existed between staff of different agencies with respect to service delivery methods, goals, staff roles, and funding mechanisms. Furthermore, One-Stop consumers indicated that improvement was needed in staff knowledge about disabilities and disability etiquette, staff interactions with people with disabilities, physical and programmatic accessibility, and marketing both to consumers and employers.

To address such issues, the U.S. Department of Labor (2002) sponsored a project with the Kansas Department of Human Resources and Kansas Commission on Disability Concerns to enhance One-Stop services to job seekers with disabilities. As participants in this project, our goal was to develop a training program that would raise disability awareness and self-efficacy of One-Stop staff serving people with disabilities. This increase in awareness and self-efficacy would eventually contribute to a unified culture of sensitivity toward, and an ability to work with, job seekers with disabilities.

#### Method

Since our primary purpose was to increase the disability awareness and self-efficacy of all One-Stop staff in a particular region, we used a quasi-experimental design. We administered pre and post-tests to each participant in order to evaluate the effects of training on beliefs about their ability (or self-efficacy) to effectively serve job seekers with disabilities. We chose to measure self-efficacy because as self-efficacy theory holds, psychological and behavioral change processes operate partly by altering the individual's sense of personal mastery or self-efficacy (Bandura, 1986; Goddard, Hoy, & Hoy, 2004; Lent & Maddux, 1997). Research shows that self-efficacy is a predictor of an individual's choice of behaviors, effort expended, persistence despite obstacles, and actual performance (Bandura, 1977).

## Setting

A private, non-profit business located in Northeast Kansas administers five One-Stops serving a population of over 530,000 in seventeen counties in both urban and rural settings. The One-Stop partners vary from center to center with each including community-based organizations (e.g., Goodwill, local mental health centers, Kansas Legal Services) and government-sponsored agencies (e.g., Kansas Social and Rehabilitation Services, Kansas Department of Human Resources, federally funded Job Corps programs).

## **Participants**

All 36 staff members serving in the five One-Stops participated in the training and evaluation of self-efficacy for tasks related to assisting job seekers with disabilities. The regional One-Stop administrator compelled each staff member to participate through automated limitation of computer access until the staff person completed the self-assessments and training program.

Participants' mean age was 49 years and 70% were female. Of those who identified their race and ethnicity: 55% identified themselves as White, Non-Hispanic; 12% as Hispanic; another 12% as African-American, and 6% as Native American. Participants' self-reported highest level of educational attainment varied widely: 24% of participants had attended some graduate school; 30% of participants had earned bachelor's degrees; 36% of participants had attended some college or earned an associate's degree, and 9% of participants completed high school or its equivalency. The participants averaged 14 years of experience in the field of employment assistance.

## **Training Program**

The specific objectives of this training program, as determined by the project sponsors, were to increase each One-Stop staff's self-efficacy in: (1) Ticket to Work-Workforce Investment Act and WIA benefits and services; (2) legal issues (e.g., American with Disabilities Act, Individuals with Disabilities in Education Act, Section 504); (3) disability conditions; (4) accessibility and accommodations, and (5) educational opportunities. Bandura (1982) indicates that self-efficacy develops through success experiences, vicarious learning, verbal persuasion, and physical state/reactions thus, we designed the training program to rely upon the first three of these elements.

In order to determine the specific content of the training, we conducted focus group interviews with staff members of the five One-Stops, held meetings with independent living and mental health center staff in each community, and contacted relevant government agencies (e.g., National Center on Workforce and Disability, National Council on Disability, Employment and Training Administration, Southeastern Disability and Business Technical Assistance Center). During focus group interviews, we learned that time for face-to-face, group training of each One-Stop staff is very limited. Therefore, we chose to develop an Internet-based training program, which staff could access individually at times most convenient for them. This delivery system had the added benefit of immediate availability to future staff members who might also need to learn the content and skills important for assisting people with disabilities.

The focus group interviews with the One-Stop staff members showed that their role in the One-Stop was more like that of a librarian rather than that of a case manager. They were expected to be adept at directing job seekers to the wide range of resources available at the One-Stop. Included in those resources were disability-related information, which either they or a job seeker could access on an as-needed basis.

Therefore, we organized the Internet-based training curriculum into ten modules, which could provide opportunities for verbal persuasion as well as serve as future reference material. The modules address:

- Defining disability
- Basics of working with people with disabilities
- Disability policy and benefits
- Issues related to specific disabling conditions
- Features and use of an accessible workstation
- Career guidance
- Resource checklist
- Learning disability screening
- An interactive database of community resources
- Information for employers

We conducted five face-to-face training sessions at each One-Stop to "jump start" the use of the Internet-based training, giving One-Stop staffs opportunities for vicarious learning from project staff. Additionally, project staff facilitated hands-on training and success experiences with assistive technology.

## Defining Disability Module

Considering that legal definitions of disability vary considerably, this training module addresses differing definitions and relates them to One-Stop services. For example, a person may

be considered disabled under ADA but not by their state's VR agency, which relies on the definition provided by the Rehabilitation Act. Under WIA regulations, disability status is determined using the ADA definition. On a practical level, this means that some people who utilize One-Stop services and are considered to have a disability will not meet the more restrictive definition under the Rehabilitation Act. Therefore, they will not be eligible for intensive services from VR.

The module also addresses practical issues with the definition of disability. For example, not all disabilities are visibly evident (e.g., learning disabilities, multiple sclerosis, epilepsy) and thus, One-Stop staffs are advised to never assume that a job seeker does not have a disability just because one is not readily apparent. Conversely, not all visible conditions meet the specific criteria for disability (e.g., not all people who wear glasses have a disabling visual impairment) or a condition may be controlled through medication (e.g., depression) and thus, is only a minor factor in employment decisions.

## Basics of Working with People with Disabilities Module

This module presents guidelines for interacting respectfully with people with disabilities. One-Stop staff can learn basic information about disability etiquette, disclosure and confidentiality, accommodations, and self-advocacy. For example, the module teaches staff to always use person-first language (i.e. "person with a disability" not "the disabled", or "person who is blind" not "a blind person"). Staff are reminded that people with disabilities, like all people, are experts on themselves; they know what they like, what they do not like, and what they can and cannot do. Staff interactions with job seekers with disabilities demands respectful, polite communication as with any other job seeker.

The module addresses issues related to disability disclosure and confidentiality from the job seeker's point of view. One-Stop staffs learn that a job seeker may choose whether and when to tell an employer that he or she has a disability, the advantages and disadvantages of disclosure, and how a job seeker might go about disclosing a disability to a potential employer. Under the ADA, a person with a disability can choose to disclose at any time and is not required to disclose at all unless he or she wants to request an accommodation or wants other protections under the law.

Staff learn about the reasonable accommodations job seekers may request from employers, that is, any change in the work environment or in the way things are usually done in order to provide an equal employment opportunity for a person with a disability. The type of accommodation depends on the person's abilities and limitations and many individuals with a disability will not need any accommodation. Employers must provide reasonable accommodation unless the accommodation will cause an undue hardship (i.e., an action that is too difficult or costs too much money in relation to the size of the business).

Some job seekers with disabilities may lack the self-advocacy skills required to disclose a disability and request an accommodation. Staff learn to assist such individuals in becoming more comfortable with disclosure by providing information and role-playing. To assist the job seeker to successfully self-advocate, an individual needs to know the following: His or her rights under the law; Facts about his or her disability; Essential and marginal job functions of jobs he or she is interested in; Potential accommodations that would allow performance of the essential functions of the job, and ways to approach employers that will encourage positive rapport.

## Disability Policy and Benefits Module

Perhaps the most difficult topic in the training program addresses government benefits available to people with disabilities. In particular, staff learn how a successful job search and employment affects program benefits. Program benefits explained in this module include Social Security Disability Programs, Ticket to Work, Medicare, and Medicaid. Staffs learn about benefits planning, assistance, and outreach. In addition, the module guides them through disability-related topics such as protection and advocacy issues, continuing disability reviews (CDRs), expedited reinstatement of benefits, trial work period, substantial gainful activity (SGA), and student earned income exclusion.

# Issues Related to Specific Disabling Conditions Module

The possible challenges for people with specific disabilities in the workplace and possible accommodations for these individuals are presented in this training module. Detailed information on approximately 40 disabling conditions, common limitations connected with them, useful questions to consider, and accommodation possibilities are available through Internet links to the Job Accommodations Network Website (www.jan.wvu.edu). The information provided by this module may have its greatest value as a reference tool for staff when actually serving a job seeker with a specific disability.

## Accessible Workstation Module

Adaptive equipment or assistive technology devices available in the accessible workstations in the five One-Stop locations for use by job seekers with disabilities are explained in this module. For each device the module provides answers to the questions: (a) what is it? (b) who uses it? (c) how do you use it? and (d) where to get more help? The staff members can look up devices by equipment type (e.g., computer, telephone, printed materials) or by special need category (e.g., blind/low vision, deaf/hard of hearing, limited hand use, learning disability).

#### Career Guidance Module

This module provides information on job hunting and career decision making for all job seekers, not just those with disabilities. Topics include: Job Search 101; Recipe for Successfully Choosing Work; Overcoming Barriers to the Job Hunt and Employment; The What, Where, and How of the Job Hunt; The Role of Career Testing; Further Training; Resumés, and Job Interviews. The module also provides examples of successful workers with disabilities and additional Web resources. Embedded into each of the training texts are Internet links to Web sites that provide additional information and up-to-date resources.

#### Resource Checklist Module

One-Stop staff learn and teach job seekers to use a checklist identifying potential resources the job seeker may need. Job seekers answer a series of "Yes" or "No" questions, such as, "I have good reading skills", "I have concerns about childcare", "I would have problems with transportation to and from work", or "I am the main caregiver for an elderly person." After the

job seeker answers these questions, the Web site selects and displays a personalized list of up to 20 community resource category links that may be helpful to the job seeker (e.g., abuse and assault, child care, counseling/mental health, credit/financial counseling, disability services, education). Job seekers are encouraged to use this checklist with the One-Stop staffs as a means of discussing their particular issues and needs regarding the job search process.

## Learning Disability Screening Module

The Adult Learning Disabilities Screening (ALDS) is a short set of questions used to decide whether a person ought to be fully tested for a learning disability. In basic terms, a learning disability is defined as a disorder in understanding or in using language, spoken or written, which may appear as an imperfect ability to listen, think, speak, write, spell, or to do mathematical calculations.

Persons with learning disabilities have average to above-average intelligence, but may have difficulty in school and later in other activities like keeping a job or meeting obligations. Therefore, One-Stop staff may suggest job seekers complete the ALDS questions about daily activities at work, home, and in the community (e.g., "I like to read" and "I have a hard time getting along with others") using a Likert scale and a self-administered inventory with "Yes" or "No" questions about health, family, and education (e.g., "Have you ever had difficulties with attention or concentration?" and "Have you ever received special education services or been placed in remedial classes?"). If a job seeker's ALDS results so indicate, One-Stop staffs may arrange for additional assessments for cognitive disabilities and job accommodations.

## Community Resources Module

In this training module, One-Stop staffs become familiar with a searchable community resource directory for the Northeast Kansas region. Resources listed in the Community Resource Directory are only those located in the seventeen counties served by the five area One-Stops. Staffs and job seekers alike can search this directory in different ways, such as zip code to find agencies in one area only, the name or part of the name of an agency or organization, all the agencies and organizations that might help with one of the categories (i.e., abuse and assault, child care, counseling/mental health, credit/financial counseling, disability services, and education), or a user-determined keyword.

## For the Employer Module

One-Stop staffs learn reasons why an employer should hire someone with a disability. For example, several industry surveys show that employees with disabilities have low turnover rates, low absenteeism, and high productivity. Furthermore, employers may receive tax credits and incentives from state and federal governments. For each tax incentive, the module explains what it is, who is eligible, the amount available, which expenses are covered and which are not, how the incentive can be claimed, minimum requirements and limitations, and where to obtain additional information. Federal tax incentives for employers who hire people with disabilities included in this training module are: (a) Small Business Tax Credit: IRS Code Section 44, Disabled Access Credit; (b) Architectural / Transportation Tax Deduction: IRS Code Section 190, Barrier Removal, and (c) Work Opportunity Tax Credit (WOTC). State of Kansas Disabled

Access Credit for small businesses that make their businesses accessible to persons with disabilities is also explained in the module.

In addition to the reasons why an employer should hire people with disabilities, this module explains the reasonable accommodations they can make when hiring people with disabilities. Staff learn about modifications or adjustments (a) to a job application process that enable qualified applicants with disabilities to be considered for available positions, (b) to the work environment that enable a qualified individual with a disability to perform the essential functions of that position, and (c) that enable an employee with a disability to enjoy equal benefits and privileges of employment as are enjoyed by similarly situated employees without disabilities.

The One-Stop staffs learn about practical issues faced by employers. They are prepared to advise employers about what makes an accommodation reasonable or an undue hardship. They learn about what an employer can request as documentation when an accommodation is sought, whether they may require an individual to accept an accommodation that he or she did not request, and who pays for the accommodation. The module explains ways to identify reasonable accommodations for specific disabling conditions and provides many examples of situations an employer may encounter and possible solutions.

#### Assessment Instrument

Self-efficacy is a task-specific construct necessitating a task-specific rather than standardized assessment instrument. To measure a One-Stop staff's self-efficacy with regard to their knowledge of and ability to work with adults with disabilities, we developed a context-specific self-assessment instrument. Project staff created the assessment items based on the focus group interviews and prior knowledge. One-Stop administrators reviewed and edited them for relevancy and readability.

The instrument presents three scenarios with nine questions each (see Figure 1), along with five sets of topical questions addressing legal issues, disability etiquette, accessibility issues, general questions, and other resources a One-Stop staff person may access while assisting job seekers with disabilities. The fifty-one-item assessment utilizes an eight-point Likert-like scale for indicating the participants' level of confidence, with zero representing "almost no confidence" and eight representing "almost complete confidence." Coefficient alpha, a measure of the reliability of the fifty-one items summed to form a scale, was .97.

#### **Procedures**

#### Pre-test

During a two-week period in 2003, 36 participants completed the Internet-based self-assessment of their knowledge and self-efficacy for tasks related to assisting job seekers with disabilities. Results were compiled by project staff and held for later analysis.

## **Training**

Project staff conducted a total of five face-to-face training sessions at each One-Stop site to introduce the on-line training tools and the disability awareness self-assessment survey. The

onsite training included two visits to each site to cover training on specific equipment (e.g., TTY, Braille printer, computer software, hardware for persons with visual disabilities). In addition, one session at each site covered the basics of career counseling and how to use the Web site resources in that role. Finally, two sessions at each site focused on assessing and dealing with job seekers with disabilities and in general disability services.

#### Post-test

About a year later, the same participants completed the same self-assessment. The second self-assessment provided us with an overview of how confident staff members were at the two different times in dealing with those issues, allowing some sense of how much their confidence might have changed as a result of the training program as well as other experiences during the intervening year.

## Data Analysis

Project staff tabulated pre and post-test results for the 36 participants. Researchers performed statistical analysis of the results, including factor analysis as well as t-tests and correlations.

#### Results

Given that this study was a quasi-experimental design, there is no way to know with certainty how much, if any, change in self-efficacy from pre to post-test was due to this specific training or other variables such as other training received or personal experiences on or off the job. Nonetheless, at least some of the changes from pre- to post-test were likely effects of the training.

A principal components analysis utilizing a varimax rotation failed to yield any solution other than a single factor solution. An oblimin rotation did no better, again yielding a single factor structure. We found no significant correlations between self-efficacy and several other variables collected from the staff, including age, years of experience, years of education, and gender.

The mean score on the pre-test was 267.9 (SD = 64.8). On the post-test, the mean was 274.2 (SD = 57.7). A one-tailed paired samples t-test, which compared staff members' pre-test scores to their post-test scores, was significant at the .05 level, signifying a small but statistically significant increase in self-efficacy from pre-test to post-test.

A paired samples correlation of pre-test scores and post-test scores was .80, showing an expectedly strong relationship between a person's score at pre-test and their score at post-test. In other words, staff members who were confident in their abilities to handle various disability-related situations at pre-test continued to be confident at post-test, with modest improvements across most staff. Of the 36 staff members, seven showed minor decreases in confidence from pre to post-test, one showed no change, and 28 showed increases in confidence.

Table 1 lists the five items with the greatest increase in mean score from pre-test to post-test scores and the seventeen items with decreasing mean scores from pre-test to post. (Contact lead author for complete listing of results). For normative comparisons, any item with a mean below 4.4 is considered low and any item with a mean above 6.0 is considered high. An

individual total score for all fifty-one items that is below 225 (about one standard deviation below mean) could be considered low self-efficacy, and a score above 300 (about half a standard deviation above mean due to a skewed distribution) could be considered high self-efficacy. Eighteen items (35%) in the assessment had mean post-test scores above the high threshold (M > 6.0). The six highest of these items represented simple tasks (e.g. directing someone to the accessible telephones) or common activities also performed for able-bodied job seekers (e.g. refer to housing agencies or childcare providers). Fourteen items (27%) had mean post-test scores below the low threshold (M < 4.4). All low items were solely disability-related tasks.

Figure 1 shows the pre- and post-test scores by One-Stop Workforce Center. Although all sites increased in confidence from pre to post-test, some sites demonstrated slightly more confidence than other sites (n=27, site information was not available for all participants).

#### **Discussion and Conclusions**

The task of building a culture that is sensitive to the needs of job seekers with disabilities is certainly larger than a single training program. However, staff development can be a key component to the building process. We observed that after one year of experience and a series of training activities, staffs self-efficacy for serving people with disabilities increased a statistically significant amount overall, without any correlation to age, gender, years of experience, or years of education. Further, self-efficacy increased from the pre to post-test in each One-Stop, indicating that place also was not a distinguishing factor in the changes.

Individual item analysis yielded some insights into the overall increased self-efficacy. For example, self-efficacy for the use of TTY/TDD for incoming calls increased 1.67 points, more than any other item in the assessment. Pre-test self-efficacy for this skill was low (M = 4.33), but after training, posttest self-efficacy was high (M = 6.00). One possible explanation for this large increase is use of the TTY/TDD equipment is a simple skill in which many staff had no prior training or experience. Another explanation for this particular self-efficacy increase is that a project staff member monthly tested TTY/TDD skills by placing incoming calls to each One-Stop location. This project accountability measure may have increased motivation for all staff to learn the skill and for those who answered the calls, created successful experiences.

The next three largest changes in self-efficacy were increases in: (a) explaining the ADA definition of "disability" (pre-test M = 4.24, post-test M = 5.30); (b) setting up a job coach (pre-test M = 3.82, post-test M = 4.57), and (c) helping customers use a device that magnifies printed material (pre-test M = 3.52, post-test M = 4.20). We can only speculate about why these items increased more than others. For example, self-efficacy in defining disability according to the ADA might have increased because the ADA is the standard under which One-Stops operate. Thus, staff potentially experienced repeated successes as they explained to incoming clients what it means to have a disability. Perhaps staff had similar successful experiences with the other two tasks as well. The training modules provided staff with readily accessible information that was a foundation for improving content knowledge or specific procedural knowledge.

Not all skills we assessed resulted in an increase in self-efficacy. In fact, eighteen (35%) of the fifty-one items decreased in mean score. Self-efficacy in orienting a client with a disability to the One-Stop's accessible workstation, a seemingly simple task at first blush, dropped 0.50 points from M = 5.85 to M = 5.37. Likewise, self-efficacy in helping a client with a disability determine strengths for employment and serving a client whose disability is unfamiliar to the

staff person also decreased by 0.40 points. Decreases in post-test scores may be explained by the curvilinear relationship between self-efficacy and training (Sipps, Sugden & Faiver, 1988). One-Stop staff may have underestimated the complexity of these tasks thus, initially exhibited higher self-efficacy. Self-efficacy may have decreased because training or actual experiences persuaded them to see the tasks as more complex.

The three items with low pre-test self-efficacy that dropped even lower in the post-test deserve more discussion. These items: (a) helping screen customers for possible learning disabilities (pre-test M = 3.88, post-test M = 3.63); (b) helping a client with a disability obtain more information about the Ticket to Work program's Medicaid buy-in (pre-test M = 3.97, post-test M = 3.87), and (c) obtaining a sign language interpreter for customers (pre-test M = 4.52, post-test M = 4.33) directly address the objectives of the training program. In order for One-Stops to successfully serve job seekers with disabilities alongside job seekers from the general population, staff need to have basic knowledge about topics like learning disabilities screening, the Ticket to Work program, sign language interpreters, and other similar disability-related programs and activities. During the pre-test, staff knew that they did not know much about these topics and after a year of experience and training, they believed they knew even less. Although these self-efficacy decreases may be a function of staff more fully appreciating the complexity of the tasks, the absolute level of efficacy should be of concern to One-Stop administrators.

#### **Future Directions**

The fact that pre and post-test scores did not reflect large differences would suggest that training methods should be improved. For example, the training team could include one or more persons with disabilities, increasing opportunities for success experiences and vicarious learning (Bandura, 1982). Similarly, like with the TTY call-back strategy, more opportunities for handson successful experiences could be provided. Finally, "field testing" staffs by sending job seekers with disabilities to evaluate their responsiveness may be incorporated as an accountability measure.

Training is just one way to increase a staff efficacy in serving job seekers with disabilities. Other factors that might improve a center's ability to meet the needs of people with disabilities could include making prior knowledge of disability issues a hiring criterion, requiring more than a high school diploma, changing staff roles from that of "librarian" to that of "navigator", having supervisory staff communicate and model a moral imperative regarding services directed toward persons with disabilities, making structural changes toward accountability systems and external rewards, and implementing an overall customer service orientation. Such efforts can serve as catalysts and sustainers of change in interactions between consumers and staff. The established social structure of any organization is a critical attribute, to the degree that one can succeed in improving the self-efficacy among staff and change the social structure so that it better serves the needs of job seekers with disabilities.

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In the interest of demonstrating the bridge from research to practice, readers may want to visit the website referenced in this essay. It is currently maintained by the Kansas Commission on Disability Concerns. Our work is part of a larger website titled Kansas JobLink, and may be found at http://www.kansasjoblink.com. Through the link labeled Disability Resources you will find most of the modules discussed here. To access the complete set of modules, most notably, the Disability Awareness Tool used as the assessment instrument requires that you create a job seeker account at the website's homepage.

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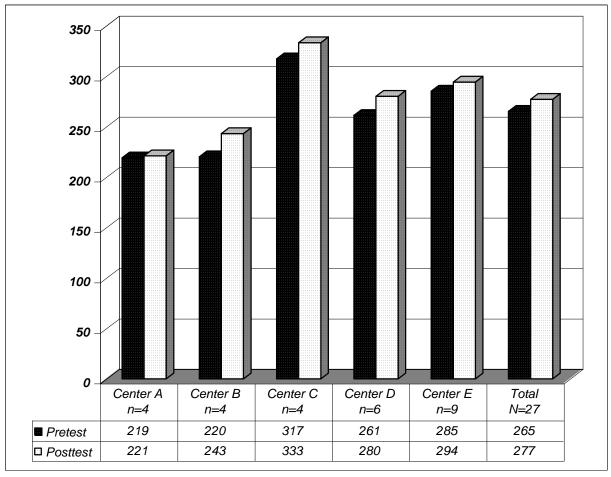
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Table 1 One-Stop Staff Self-Efficacy Greatest Increases and Decreases from Pre- to Post-test

	c-stop start sen-Efficacy Greatest increases and Decreases fro	Pretest	Posttest	Difference
	Greatest Increasing Scores			
1.	Use the TTY/TDD to help customers who call the Workforce Center.	4.33	6.00	1.67
2.	Explain the ADA definition of "disability."	4.24	5.30	1.06
3.	Set up a job coach for Luis.	3.82	4.57	0.75
4.	Help customers use a device that magnifies printed material (i.e. Optelec Clearview).	3.52	4.20	0.68
5.	Refer customers needing on-the-job accommodations to other resources.	4.91	5.47	0.56
	Decreasing Scores			
1.	Help Luis obtain more information about the Ticket to Work program's Medicaid buy-in.	3.97	3.87	-0.10
2.	Select appropriate tools to assess Maya's vocational interests.	5.06	4.97	-0.10
3.	Explain basic Vocational Rehabilitation services to customers.	5.09	5.03	-0.10
4.	Obtain more information about Luis' specific disability.	5.79	5.67	-0.10
5.	Identify community agencies that could help Maya achieve her employment goals.	6.18	6.10	-0.10
6.	Obtain a sign language interpreter for customers.	4.52	4.33	-0.20

Figure 1 Average Pre- and Post-test Self-Efficacy Scores by One-Stop Workforce Center



Essays

# Impact of the South Asian Earthquake on Disabled People in the State of Jammu and Kashmir

Parvinder Singh, Ph.D. Candidate Jawaharlal Nehru University

**Abstract:** On the morning of October 8, 2005, a devastating earthquake, measuring 7.6 on the Richter scale, struck the Kashmir region with its epicentre near Muzzafarabad in Pakistan-administrated Kashmir. It took a while for both India and Pakistan to comprehend the scale of destruction that the quake had unleashed. In the two weeks following, the quake had left over 50,000 dead on the Pakistani side of the India-Pakistan border and claimed 1,300 lives on the Indian side. A second wave of deaths was expected with the onset of the region's notorious winter.

Our thoughts immediately went to what may be happening to disabled people in the State of Jammu and Kashmir, though we knew the answer, based on our bitter experiences of seeing disabled people being neglected even in the so-called normal scenarios. Our National Disability Network partner in the mountainous and violence ravaged State confirmed our fears of the "general neglect" being compounded in the wake of this calamity.

With information gained from the Asian Tsunami and impending legislation on Disaster Management on the floor of Indian Parliament, we decided it was imperative to draw up the difficulties that disabled people face during natural disasters to facilitate some churning of our national consciousness and possibly a policy intervention. What follows is an account of a fact-finding mission, its findings and recommendations, on the impact of the Kashmir quake. It is a story of persistent neglect, which turns grave when calamities strike.

**Key Words:** disaster, Kashmir earthquake, disability

#### Introduction

Late last year, a devastating earthquake shook the Himalayan region of the Indian subcontinent. The two rival nations, India and Pakistan, were united in grief as the scene of death and destruction unfolded. But as this event showed, just like Hurricane Katrina almost halfway across the globe, those who are collectively consigned to the margins of policy focus and safety plans are not only the worst sufferers of disasters, but also the least attended. India did not have a disaster management policy when the South Asian Earthquake took place. It was in a phase of finalisation. But the policy makers once again failed to focus on the needs of over 700 million disabled and aged people, as the final draft of this plan did not make even a single mention of these sections of the population.

# Impact of South Asian Earthquake on Disabled People

On the morning of October 8, 2005, a devastating earthquake, measuring 7.6 on the Richter scale, struck the Kashmir region with its epicentre near Muzzafarabad in Pakistan-administrated Kashmir. However, it took a while for both India and Pakistan to wake up to the scale of destruction that the quake had unleashed. In just the two weeks since, the quake had left over 50,000 dead on the Pakistani side and taken 1,300 lives in India. The toll rose substantially by the second wave of deaths with the onset of the region's winter.

Immediately after the quake, the National Centre for Promotion of Employment for Disabled People (NCPEDP), Disabled Peoples' International – India (DPI – India), and the National Disability Network (NDN) contacted the NDN State Partner, Javed Ahmad Tak of Helpline, a Non-Government Organization (NGO) working for the rights of disabled people in the remote parts of Jammu and Kashmir. Through him we came to know stories that went beyond what the newspaper headlines could capture, particularly with regards to the status of people with disabilities. Their plight was multiplied manifold due to the reported lack of coordination and inaccessibility.

With these concerns in mind, a team consisting of myself, Senior Project Coordinator with NCPEDP and Mukhtar Ahmad and Muzzamil Yakub, both from a local disabled peoples' NGO Helpline, visited quake affected areas in Kashmir from October 18<sup>th</sup> to 20<sup>th</sup> to take first hand stock of the status of the rescue, relief, and rehabilitation process with a specific focus on

people with disabilities. The objective was to get disability included in the long-term rehabilitation plans being mooted by sensitising the State's polity and the civil administration. Further, we also wanted to understand the disability scenario in the region: the administrative framework, implementation of the Disability Act, and the existence of disability NGOs—including their functioning, reach, and awareness levels that will help in planning their work for the future.

We visited hospitals, relief camps, and villages in Baramulla, Uri, Tangdhar, and Salamabad. During the course of our visit, we contacted the Honourable Governor, Lieutenant General Shri S.K. Sinha, State Social Welfare Minister Shri Mula Ram, and the State Human Rights Commissioner Justice A. Mir. We also spoke to other personnel, including several local officials, medical staff, and doctors, as well as quake-affected people. But before detailing our first-hand experience of the chaos and ordeal of people in the State, it is important to conceptualise the unique and not so-unique aspects of the State, particularly its status as a conflict zone.

# Kashmir: Disaster and Disability in a Conflict Zone

The State of Jammu and Kashmir has had a history of violence and political turmoil ever since India and Pakistan attained political independence from British rule in 1947. The two neighbours have fought full-scale wars in 1947 and 1971, besides a near-war like conflict in 1999 called the Kargil War, over the region. The bone of contention between the two nations has been the treaty of accession that was signed by the then ruler of Jammu and Kashmir and Lord Mountbatten in 1947 through which the state was ceded to India. Pakistan has refused to accept this fact.

The State was thrown into turmoil in the 1990's as Islamic militancy grew roots in the region and enlisted thousands of local youth into the vortex of violence. Today the State has the largest deployment of soldiers and para-military in any single region in India. This conflict combined with political discontent among the locals has given birth to an extremely complex sociophysiological situation in the State. Deaths, gunfire, blasts, disabilities, and unaccounted disappearances have subjected the local population to trauma associated with a conflict zone for several years. The impact on vulnerable groups has been severe, particularly women and disabled people. A number of civil society groups are engaged in providing support to a wide social group undergoing mental health issues, including widows, rape victims, and orphaned children.

The State dubbed by many past rulers as "a heaven on the earth" for its breathtaking mountainous beauty, offers difficult living conditions due to its severe winters and inaccessible terrain that is compounded by poor infrastructure. The people here are predominantly Muslim and have a strong ethnic identity. A large part of the State formed a very volatile border with Pakistan until a recent cease-fire agreement came into force. The cross-border shelling and heavy artillery fire has been a constant feature for people living in the bordering villages. This shelling and artillery fire has been a major cause of physical disability, along with insurgency related causes.

It needs to be underlined here that, at least so far as our Indian experience is concerned, disabled people and issues related to them are way down the list of social and administrative concerns as the so-called pressing issues that confront a much larger or visible vote-bank are given a precedence. This situation holds true for Jammu and Kashmir as well. However, what

makes it worse here is that the agenda of development has found a very myopic interpretation here, as this unending violence has not allowed any sustained growth.

Various institutions like schools and hospitals reflect a lack of even basic accessibility features. Javed, our local disability NGO partner, has been fighting for years now to get some disability-friendly changes initiated in the Kashmir University. After each incident of violence that gets noticed nationally, authorities almost spontaneously issue token compensation and artificial limbs to disabled people. This effort, however, is never sustained to make those affected economically and socially independent. Curfews are an order of the day in the streets of the Kashmir Valley and incidents abound of people being shot in the dark of the night because they were too slow in responding to a call by troops to move away or step into the light. Problems of sanitation, portable water, and transport make life for disabled and aged people very tough.

# Relief Distribution Left Disabled People Unattended

After the earthquake, it was a clear display of the Darwinian theory of the survival of the fittest when it came to relief distribution, which for the most part was a hit-and-run drill of dumping relief materials by NGOs, political parties, and charitable trusts. This scene was apparent all along the National Highway No. 1/A from Baramulla onwards. Though there was plenty of aid, the takers of the relief material distributed through this method were ironically very limited in number. These were largely young boys who could slug it out in the jostling crowd. We saw this at least at a dozen points starting from the outskirts of Uri.

As we spoke to persons with disabilities who received aid, we were astonished by their stories. One said:

"I have walked here with great difficulty. My braces are my only mode of travel as the artificial limb that was given to me by the Indian Army at the Bone and Joint Hospital in Srinagar (winter capital of India-administered Kashmir) has cracked and I will need a new one... There is a mad rush when relief is being distributed. People are desperate. My father is very old and I have five sisters. This makes me the only one in the family who can come out and hunt for relief. My house has got destroyed completely and we have been camping in the open for past eleven days."

The 22-year-old man had lost his right limb a few years ago when a shell landed on his house. He was trapped in the ensuing fire. He had been trekking over seven kilometres each day, since his house was destroyed in the quake, to the District Medical Centre in Uri to try his luck and get some blankets.

This experience is indicative of why a targeted approach is needed for people with disabilities, who face unimaginable difficulty in accessing relief in times of disasters. This problem was compounded in the case of Kashmir due to its mountainous terrain and the general inaccessibility of the region. The small settlements in the area defy the usual conception of a village and might be no more than a set of six to eight houses far from the navigable road. As I moved around the fringes of the highway that led to the neighbouring Pakistan border, I kept hearing of families stuck near their destroyed dwellings in the hills as the able-bodied male members came out to get in touch with lower-level government employees who almost always double as relief workers in case of calamity.

The Uri region has been a focal area for projects run by state power and construction companies. They were one of the first institutions, after the Indian Army, who had set up relief and first aid centers. I spoke to some of the officials manning these and was told that they had not seen any disabled person coming over from the villages in the hills. "It is unlikely that a disabled person would trek so far in these circumstances. We have sent teams out on foot, but in my knowledge they have not reported having met any in this area (Salamabad)," said an official manning a small centre set up by Hindustan Construction Company.

My personal observation revealed three disabled people slugging it out in the crowds that had gathered at relief distribution points. This struggle for relief material brought to my mind the general neglect that disabled people face in the country on account of lack of policy focus, which in turn is fostered by lack of empowerment and awareness among people with disabilities.

Lack of Coordination and an Existing System with Specific Focus on Disabled People

According to an estimate of the disability sector, there are over a million people with disabilities in the state of Jammu and Kashmir. A large number of these people have been disabled due to incidents relating to mine explosions, shelling along the Line of Control, and militancy-related violence. In view of the above situation, the lack of attention that the civil administration and its officials displayed in terms of attending to people with disabilities came as a surprise.

As happens after every disaster in the sub-continent, the employees of Union and State governments are rushed to these areas to open rather ill-equipped so-called relief centres. These junior-level employees are not trained to deal with such scenarios. "There is no specific brief to be kept in mind so far as disabled people are concerned. I will definitely help them on account of humanity. We know things can be tough for them," said an official at a point set up by the National Hydro Power Corporation.

We visited an Information Centre set up by the State Administration outside the Sub Divisional Magistrate's office in Uri to find out if any disabled people had approached them for help. The officials on duty told us in general that those approaching them were NGO workers, and not victims. "Can you tell me what villages we can go to? I have been waiting to find an area where we can help victims affected by the quake...it has been two days," said David Martin from US-based charity called Helping Hands. "All of us have been affected by the quake. Why are you enquiring only about people with disabilities? They will ultimately receive some help," said an official outside the District Hospital in Uri.

My interaction clearly brought out the general lack of coordination. People from affected villages blamed politics or apathy as the reason for the lack of timely relief. It also highlighted the absence of orientation towards the needs of disabled people.

# Quake Injuries Indicate A Likely Rise in Disabilities

During our visit to hospitals in Baramulla, Uri, and Srinagar we attempted to take stock of the kind of treatment people with disabilities needed, the assistive or orthopaedic devices they needed, and the nature of the injuries that were being reported. Dr. S.A. Rashid, Medical Superintendent of the Bone and Joint Hospital in Srinagar stated:

"The true picture of rehabilitation that these victims will need would emerge only in the coming months. Most of these injuries were caused by dislodged objects. Quite a few of these people would not be able to function as before. There are cases of compound fracture that may get complicated, and some of them may even need amputation."

The office of Medical Superintendent at Sher-e-Kashmir Institute of Medical Sciences voiced the same opinion. Doctors on duty said that the majority of the 211 cases related to the earthquake were of injuries to the limbs and head. Dr. Samina of Sher-e-Kashmir Institute of Medical Sciences added that:

"Three amputations have taken place so far (till 20th October). These include two men and one girl. They have been referred for surgery. In fact the girl's amputation was done today itself."

I also observed reluctance on the part of doctors and hospital medical staff in sharing information, possibly because of heavy politicisation that saw leaders of all hue frequenting these hospitals.

Dr. Jatinder Singh of the Bone and Joint Hospital in Srinagar told us of three amputations in his hospital. He also mentioned that several other cases could end up with amputations. For instance, he added a seven-month-old infant had suffered multiple fractures and was brought in 12 days after the earthquake and there was a great chance that he could end up with a disability. He also informed us about one patient, Khalid, who had a disability on account of severe dislocation of a knee and was now on the verge of amputation, even as the doctors were trying to save him from it. These visits clearly highlighted the need for both immediate and long-term intervention for providing aids and appliances, apart from medical intervention to avoid or minimise instances of disabilities.

I was also told about a team of doctors from the National Institute for the Orthopaedically Handicapped, Kolkata [Calcutta], having visited these hospitals and meeting some of the victims who have undergone amputations. But as highlighted by the doctors, there is a need for more organized and exhaustive undertakings.

I came across some NGO workers who were engaged in counselling of victims suffering from trauma. One such group, from Delhi, was manning a small centre beyond Salamabad, barely 5 kilometres from the Line of Control (unofficial India-Pakistan). "In a single day we have received about 120 people coming in for the first time since the quake. Most of these people have very minor problems and are here more because this is their first touch with compassion, after being shocked and traumatized by the destruction and death around them," said an NGO worker.

The valley has had a known prevalence of trauma cases since the time insurgency took root, and with the quake it is going to increase. We felt that the people need a greater engagement by the way of easy and accessible counselling, as short-term/temporary measures would not help.

Rehabilitation Must Take A Macro-Approach to Integrating the Needs of Disabled People

Moreover, Commanding Officer of 56 Rashtriya Rifle, an elite anti-terrorist unit of the Indian Army that operates in the Uri sector stated that:

"As our men were close to the area of impact and are well-versed with the topography here, we reacted immediately to carry out rescue operations. We continue to coordinate with the administration and civilians in getting across the relief. But our role cannot be long-term or stretched beyond a point. The civil administration will have to step in and rehabilitate the people affected by the quake."

This quotation sums up the challenge with which the civil administration is confronted. This phase of rehabilitation in Kashmir is going to be as important as that of relief, as the availability of a cover over the head would mean a difference between life and death.

"Our homes have got destroyed by the wrath of nature. As it is, the life is difficult here. We are among the lucky few who are putting up in the tent city. But we will have to return to pick up pieces and rebuild our lives," said Noor Mohammad who is putting up at the tent camp near Tangdhar, an area which has sustained the greatest damage on the Indian side of Line of Control, in terms of property. While some families in Tangdhar and Uri districts have decided to reconstruct the damaged houses using re-usable material, the state government is providing each of them with financial assistance of Rs. 100,000 [100,000 rupees] for reconstruction work. In addition, 450 engineers of the state government are being trained in two batches to guide families in rebuilding their damaged houses. Building demonstration centers are also being set up in six places in the two districts.

Almost 26 villages have been adopted by various agencies including the Army, Air Force, Border Security Force, the National Hydro Power Corporation (NHPC) and the Delhi Government. But on the projected requirement of 30,000 tents, the Government has managed to procure just over half that number.

Despite two major disasters in recent years, the Asian tsunami and the Kashmir earthquake, governments have failed to wake up to the need for placing an administrative system in place to make special provisions to ensure expeditious rescue and relief for disabled people. The long term policy measures that have been announced since then also do not reflect any learning on the part of the governments on the devastating impact that disasters have on disabled people who are not only worst hit, but also last to get any rehabilitation. An explanation for the complete neglect of disabled people by policy makers can be found in the corresponding lack of awareness and political rights of disabled people in this part of the world. A society and polity attuned to the rights of its marginalised sections is the only solution for an effective and inclusive disaster policy.

Another issue that will have to be addressed is that of the lack of a technical knowledge-base that impedes a systematic response to these disasters. The chaos that follows these disasters is also responsible for overlooking marginalized sections of the population. The training of disaster response teams and civil and administrative coordination in such situations would have to be addressed and while doing so the needs of vulnerable sections would have to be prioritized.

# Recommendations

Following this visit, we made following broad recommendations to the Government of India:

- 1. There is an urgent need to collect data on disabled people who have been affected by the earthquake. Not only should we look at the data of those who have been rendered disabled, also that of those with a disability who have survived but are affected and people with psychosocial problems compounded or caused by the disaster.
- 2. Concrete and time-bound plans must be made to address disability concerns in revival of livelihoods, achieving convergence among all on-going programs of sustainable development, and reconstruction.
- 3. Disabled-friendly and inclusive built environments must be considered when reconstruction of shelters (temporary or permanent), schools, health centres, housing facilities, water and sanitation facilities, etc. takes place.
- 4. International and other N.G.O.s supporting the Government in relief/rehabilitation/reconstruction work should include disability on their agenda.
- 5. Disability should be a priority area for any policy that is being formulated for preparedness, mitigation and management and other efforts to prepare us to face similar challenges with confidence, and competence in the future.
- 6. This is a good opportunity to correct the mistakes. The Disability Act should be enforced in the State.

**Parvinder Singh** is a Senior Project Coordinator with the National Centre for Promotion of Employment for Disabled People in Delhi, India. He has worked as a journalist and social science researcher, and is currently working on his Ph.D. in Modern Indian History at the Jawaharlal Nehru University.

#### **Book Review**

**Title:** *Developments in Direct Payments* 

Editors: Janet Lee & Joanna Bornat

**Publishers:** The Policy Press, 2006

**Cloth, ISBN:** 10 1 86134 654 9, 320 pages

**Paper, ISBN:** 13 978 1 86134 654 4

Cost: Cloth: \$85.00 USD, Paper: \$39.29 USD

**Reviewer:** Kevin Dierks

Developments in Direct Payments, an edited volume from Great Britain, chronicles the experiences of people with disabilities since the passage of the 1996 Community Care Direct

Payments Act. The passage of this Act is the result of the advocacy work of organizations of people with disabilities, and allows government support money to be paid directly to the intended beneficiaries, age 18-65, rather than paid directly to service providers. Thirty-four authors contributed to this work, representing researchers, healthcare professionals, social workers, parents, and people with disabilities. The editors attempted to balance the philosophy and policy of direct payments with the real experiences of recipients and frontline workers.

Direct payments are basically a simple concept--government assistance funding is allocated directly to the intended beneficiaries. This concept becomes overwhelmingly complicated when it clashes head on with a legacy system that includes institutionalization, segregated care, and an extensive stream of workers and middlemen accustomed to answering to an employer other than the person with a disability. Direct payments represent a dramatic paradigm shift for all parties and this book helps the reader understand this from the perspective of the people that live it.

Direct payment users are people of all ages with a variety of disabilities and labels, and there are significant differences in enrollment and outcomes for different users. Anyone wishing to learn more about the results of ten years of experience with these systems will enjoy this collection. Despite a decade of implementation it is still found that "many key stakeholders do not know about or really understand direct payments."(p.26) This fact, combined with the advocacy driven aspect of direct payments, makes this a must read for anyone purporting to support people with disabilities.

For US readers there are some comparisons to similar support models on this side of the Atlantic, but there is much to be learned from the UK experiences.

The first two sections present an overview of the historical context in which this legislation appeared and the challenges and opportunities in going from policy to practice. In spite of the different levels of support people need to be successful with a direct payment budget, the biggest barrier appears to be lack of information. The next three sections report the experiences and wisdom of direct payment users and professionals.

The most compelling arguments for direct payments come from the direct users and frontline workers. Their stories are interesting, enraging, amazing, and ordinary all at once. A highly controversial aspect of direct payments revolves around paying existing care providers, typically family or friends, for the support they provide. This issue is explored in Chapter 13, "Carers and direct payments".

Section 5 presents the perspectives of the growing workforce of individuals employed by a person receiving direct payments. Studies reported in this section indicate these workers have less stress and higher job satisfaction, while at the same time having lower pay and poorer working conditions. Personal stories and quotes help shed light on this apparent contradiction.

The last section deals with the future of direct payments and paints an optimistic, yet realistic view. Direct payments are currently being challenged with funding limitations and the allowable scope of personal assistance workers by existing service providers, steeped in the medical model, seeking to stop direct payment users from purchasing therapy and other services that cross the line into nursing care.

Direct payments are reported as a movement, a policy, a philosophy, a social model, and most definitely a work in progress. This book provides useful information for anyone who wants to learn more about this progression.

**Kevin Dierks** has been working professionally helping people for over 15 years. He has worked assisting and supporting people with developmental disabilities for most of this time. Through this work he has been taught many things by people with disabilities, and has developed a personal philosophy and professional approach of partnering with people to support them to find and develop their own life solutions and directions. He currently works to support innovative approaches to helping people with disabilities at the Center on Disability Studies.

#### **Book Review**

Title: Disability Rights and the American Social Safety Net

Author: Jennifer L. Erkulwater,

Publisher: Cornell University Press, 2006.

**Cloth, ISBN**: 0-8014-4417-9, 272 pages

**Cost:** \$42.50, USD

**Reviewer:** Karin F. Brockelman

Disability Rights and the American Social Safety Net is aimed at an audience educated in disability or political issues. Erkulwater adds to existing knowledge by contributing a political perspective on social, demographic, and political dynamics that have shaped disability rights and Social Security legislation in America. She describes how the emergence of the social model of disability attracted disability organizations and advocacy groups focused on different disabilities. The social model views disability as the result of unaccommodating social and physical environments, whereas the medical model places disability within the individual who does not conform to social and physical norms. Instead of competing for funding, "disability organizations saw themselves as all having a common stake in ending the discriminatory treatment that all people with disabilities confronted, whatever their impairment" (p. 30).

The author highlights the momentum that Social Security Insurance (SSI) provided for deinstitutionalization in the 1970s, and the subsequent bungling of the promise of community mental health care and integration. Institutional care is much more expensive than supporting individuals to live, and receive care, in the community. These anticipated cost savings were a powerful incentive, but when people moved from institutions back to the community, many community mental health centers did not materialize, leaving individuals without services. Erkulwater explains the effects of individual federal court cases on how the Social Security Administration determined an individual's disability certification.

The information and explanations in this book are interesting, but the author's terminology is distracting at times. "The disabled" is used throughout the book. I also had trouble with the terms, "the mentally disabled" (p. 7), and "persons with mental disorders" (p. 9). Mental disability is used in reference to people with mental retardation, people with mental illness, or both groups. Since people with mental retardation are one of the three main groups on which this book focuses, I would recommend not using "the disabled." Self-advocates with have been clear about wanting to be acknowledged as people and not as "the mentally retarded." Two

alternative terminology options are, "intellectual and psychiatric disabilities," or, "mental retardation and mental illness." "Mentally disabled," is confusing because it does not accurately describe anyone. My understanding is that many do not want to use "mental retardation" anymore either.

I found chapter 8 especially informative. The chapter starts with a description of people feigning cognitive and psychological disorders to get SSDI benefits. This fraud was widely exposed by the media in the mid-1990s. Before reading this chapter, I knew about some of the factors contributing to the American public's suspicion of people who say they have hidden impairments, such as anxiety disorders, learning disabilities, and fibromyalgia. After reading this chapter, I want to learn more about the impact of economic and political dynamics on attitudes toward people who have hidden disabilities.

Disability Rights and the American Social Safety Net addresses issues of interest to those in fields related to disability and political science. Because of its richness and complexity, I think this book would be particularly useful as a text in graduate and upper level undergraduate courses.

**Karin F. Brockelman**, is currently a doctoral candidate in the Department of Special Education at the University of Illinois at Urbana-Champaign. She has a Master of Science degree in Rehabilitation Counseling and a Bachelor of Science degree in Psychology. Karin's research interest is in facilitating the success of people with psychiatric disabilities in postsecondary education, careers, and community life.

#### **Book Review**

**Title:** Going to College: Expanding Opportunities for People with Disabilities:

**Authors:** Elizabeth Evans Getzel & Paul Wehman

**Publisher:** Brookes, 2005.

**Paper, ISBN:** 1-55766-742-X, 336 pages

**Cost:** \$34.95

**Reviewer:** Rhonda S. Black

Going to College presents a well-designed and coordinated set of 21 chapters by 21 contributing authors. However, inherent in texts with material written by several authors, some information is redundant. The book is suited for an audience of professionals working in secondary or higher education who are relatively new to the area. It provides a good introduction to issues that individuals with disabilities confront upon embarking on a college education.

The book is divided into four sections. The first section, *College Planning and Admissions*, includes chapters discussing the needs and challenges associated with going to college, understanding the regulatory environment, self-determination, and the role of disability support services. The chapter titled "Understanding the Regulatory Environment" was the most

valuable. Virginia Reilly and Trent Davis thoroughly explained the ADA definition of disability and guidelines for documenting one's disability. An informative *College Accessibility Checklist* and *Additional Resources* Appendix were included adding to the utility of this chapter.

The second section, *Creating a Welcoming Environment Through Design and Implementation*, includes chapters describing Universal Design in college teaching, support services on campus, strategies for students with hidden disabilities in professional schools, the role of technology, and training faculty and staff. While the chapter on support services duplicates some material in the first section, there are unique aspects such as a specific Academic and Career Plan Form that makes the process more concrete. The chapter regarding hidden disabilities duplicates much in the third section, but discusses preparing for clinical placements and disclosure strategies in much greater detail than the following section. The Universal Design and Technology chapters are, by far, the best chapters in this section. These chapters add to the knowledge base in easy-to-read language suitable for both the practitioner and potential student. These chapters, along with a chapter titled *Training University Faculty and Staff*, are especially relevant to those who provide training for college instructors in making their courses more widely accessible.

The third section, Applications for Students with Disabilities, contains three chapters with specific information on students with psychiatric, learning disabilities or Attention-Deficit/Hyperactivity Disorder (ADHD), and intellectual disabilities. The chapter on psychiatric disabilities focuses primarily on coordination of mental health services and providing peer mentors. But, little information is provided for "how" to provide accommodations other than the need for attitudinal change. The chapter on students with learning disabilities or ADHD outlines two specific approaches – Strategic Tutoring and The Possible Selves Program. Strategic Tutoring goes beyond content area tutoring to include instruction in strategies for learning, organizing, and planning. The tutor helps the learner identify current strategies and to systematically and explicitly learn more efficient strategies when necessary. The Possible Selves Program targets student motivation by examining future goals and hoped-for possible selves. Steps include discovering, thinking, sketching, reflecting, growing, and performing. I personally enjoyed this chapter because it did not redundantly repeat the *characteristics* of students with disabilities. Rather, it provided specific strategies with discussion of research supporting these strategies, and sufficient detail that the reader could walk away with concrete implementation tactics. The chapter regarding students with intellectual disabilities provided a similar program description – the C<sup>3</sup> – College Career Connection. However, this description consisted mostly of "visioning" and planning practices, with little information on actual implementation.

The fourth and final section of the book is titled *Creating Opportunities for Employment* and includes two chapters -- *Internships and Field Experiences*, and *Career Planning and Placement*. The first chapter regarding internships discusses career development in general, and the need for career exploration and orientation. This chapter then discussed several topics discussed previously in the chapter on strategies for students with hidden disabilities in professional schools (section 2) including disclosure about disability, individualized planning, university-community partnerships and the role of assistive technology. The final chapter discusses the role of the career placement center on campus and again emphasizes the importance of job experience before graduation, and university-community partnerships.

Overall, the text provides relevant information for those in the college environment charged with making postsecondary education more accessible and supportive. Filled with case studies, program descriptions, and documentation guidelines, this text is a valuable resource for

practitioners who provide or coordinate services for young adults and adults with disabilities. However, the chapters do act more as "stand-alones" than an integrated piece of work. Much information is slightly restated in different chapters by different authors. While repetition aids in the acquisition of knowledge, this book seems to be resource guide in which the reader would select various chapters based on a specific interest, rather than a text to be read from cover-to-cover.

**Rhonda S. Black,** is an Associate Professor of Special Education at the University of Hawaii at Manoa. She teaches courses in transition, social competence, research design, and methods for general education teachers. She can be reached at rblack@hawaii.edu

#### **Book Review**

**Title:** BlindSight: Come and See

Author: Jane L. Toleno

**Publisher:** Singing River, 2006

**Paper, ISBN:** 0-9774831-4-2, 141 pages

**Cost:** \$14.95, USD

**Reviewer:** Steven E. Brown,

BlindSight is a fascinating book, both for its content and its presentation. The author, who, along with her twin, lost most of her sight, after a premature birth in the late 1940s when physicians had not yet learned about the dangers of too much oxygen, has spent a great deal of time in reflection about her life and situation. In the first of seven chapters, all of which invite us to come along with the author's journeys, she relays her internal thoughts to a phone friend's queries: "Must I have this conversation again? Don't I ever get to take time out from blindness? Why are its fingerprints found throughout my whole person, life and culture?" (p. 2) Eventually Toleno, who has clearly thought a great deal about light, dark, seeing, and not seeing, decides, "There are layers upon layers to sift and sort, name and blend here. But I think we have to talk about blindness before we can talk about light and dark." (p.4)

The author takes us along a journey exploring blindness, seasons, language, disability, and wholeness. Interspersed in her thoughts, which are by turns reflective, imploring, stern, gracious, patient, and always passionate, she includes poems essaying some of her ideas. In Toleno's essay on seasons, a poem, "After the Thaws" concludes:

We got just enough snow
To get a mile off meaning a world of work!
It was just enough snow
To force on boots, track up floors,
And blot out pointers to spring.
And there is such a hush all over the world.

It is clean and good and deep and right. It is so quiet. Can it be trusted? Sometimes, after love-making, it is like this, too. (p. 61)

This kind of unexpected juxtaposition is a hallmark of this book. Toleno plays with words and shares concepts of DarkLight, LightDark, see-ers and other ways of turning what many of us often conveniently think of as unassailable truths about perceiving the world into limitations we have been acculturated to accept. The author's manner of taking common "truths" and portraying their falseness is the most compelling aspect of her story and makes *BlindSight* a valuable addition to any disability studies or autobiographical collection.

# **Book Review**

Title: Culture and Disability: Providing Culturally Competent Services

Editor: John H. Stone

Publisher: Sage, 2005

**Paper, ISBN:** 9870-7619-3084-6, 272 pages

Cost: \$39.95, USD

**Reviewer:** Katherine T. Ratliffe

Culture and Disability: Providing Culturally Competent Services is the 21<sup>st</sup> volume in Sage Publishing's Multicultural Aspects of Counseling and Psychotherapy series. Edited by John Stone, the book is targeted to service providers, particularly counselors and social workers who work with people with both congenital and acquired disabilities and their families. Three chapters are organized around general information about working with immigrants from diverse cultures, and seven chapters address specific information about population groups from China, Vietnam, Korea, Mexico, Dominican Republic, Haiti, and Jamaica.

One of a small number of books addressing culture and disability, Stone's edited book addresses issues around working with individuals with disabilities and their families from diverse cultures. The authors define cultural sensitivity and cultural competence, place culture in the larger context of immigration patterns and globalization trends, and provide specific suggestions for service providers. For example, in their chapter introducing the concept of disability service providers as cultural brokers, Mary Ann Jezewski and Paula Sotnik present helpful strategies to bridge gaps between different cultural perspectives.

Most of the book addresses the cultural perspectives of people from the seven nations listed above. Authors of each chapter consistently address historical immigration patterns, concepts of disability, roles of family, community and religion, time orientation, and communication; and all include specific suggestions for service providers. Individuals from the cultures addressed, or closely affiliated with them, wrote each chapter, giving the work credibility. The strength of the book lies in careful attention to aspects of each culture that are

meaningful to disability service providers. Case studies in each chapter ground conceptual information in commonly encountered situations.

Although the book's detailed information is helpful, it addresses only selected immigrant groups, and does not discuss other cultures served by disability service providers such as those defined by gender, sexual identity, age, socioeconomic class, religion, and disability. The book also excludes other diverse ethnic groups in the United States such as Native Americans, African Americans, and people who immigrated from Europe, Eurasia, Oceania, Africa, or South America. The book, however, is scholarly, well written, provides comprehensive coverage of the targeted populations, and could be a valuable resource for disability service providers working with the seven immigrant groups addressed.

#### Related Books

Lynch, E. W., & Hanson, M. J. (2004). *Developing Cross-Cultural Competence: A Guide for Working with Children and their Families*, 3<sup>rd</sup> edition. Baltimore, MD: Brookes.

Royeen, M., & Crabtree, J. L. (2005). *Culture in Rehabilitation: From Competency to Proficiency*. Upper Saddle River, NJ: Pearson/Prentice Hall.

#### **Book Review**

Title: Elegy for a Disease: A Personal and Cultural History of Polio

**Author:** Anne Finger

**Publisher:** St. Martin's, 2006

**Cloth, ISBN:** 0-312-34757-X, 287 pages

**Cost:** \$25.95, USD

Reviewer: Steven E. Brown

I always look forward to Anne Finger's work and this was no exception. *Elegy* might be viewed as a memoir primarily of Finger's early years. This would be accurate, but incomplete.

The bulk of the personal narrative is a remembrance of a full, but not very happy childhood. Finger's bout with polio and its aftermath was partly responsible for this, but so too was an abusive family situation. There are interesting parallels between the violence Finger experienced as a child with a disability in her family, as a patient in the medical system, and as a person with a disability growing up in an ableist society in the 1950s and 60s in the eastern part of the United States. The most obvious commonalities are that in all situations she was the person who was powerless. She constantly rebelled against the family and medical situations, but could do very little about either one until she chose to leave her family home during her senior year in high school. She did not rebel against social norms related to disability until much later in her life.

Finger discusses the disability rights movement and disability studies and how they did and did not impact her life. Like many of us who grew up with a disability in the time period she discusses, Finger consistently and purposely did all she could to avoid even being seen with other individuals with disabilities because she did not want to be labeled in that way.

Finger also threads discussions about, and the history of, polio itself throughout the book. There is quite a lot about Sister Kenney, her background, methods, and persona. There is also a fascinating section toward the end of the book in which Finger explores polio's potential effects on the brain. She also discusses how the nature of disease itself has evolved, particularly from the nineteenth to the twentieth centuries. One result of this changing perception was that those who had polio in the twentieth century were, like many of us with varying disabilities, expected to overcome our "deficiencies."

*Elegy* is a book packed with personal and social information and will be an excellent addition to libraries and to graduate classes in medicine, disability studies, history, and sociology, among other disciplines.

#### **Music Review**

**Title:** Odd Birds

**Artist:** The Raventones (Randy Hamme & TR Kelley)

**Producer:** TR Kelley/Darkwater Music, 2003

**Title:** Starstruck Enterprise

**Artist:** The Raventones (Randy Hamme & TR Kelley)

**Producer:** TR Kelley/Darkwater Music, 2006

**Website:** http://www.raventones.com/

**Reviewer:** Kevin Dierks

Odd Birds and Starstruck Enterprise are the first and second musical CDs created and released by The Raventones, a "neurodiverse" band out of Oregon. The Raventones is comprised of two musicians, TR Kelley and Randy Hamme, who are responsible for playing and writing nearly all of the songs. TR Kelley is a lifetime musician who has demonstrated her musical talent from a very young age. She has released two solo CDs and played with "Jellymoon" after becoming famous in the 1990s as part of the band "Babes with Axes". Her talent for stringed instruments can be heard in the guitar and bass performances on these CDs. Her vocal performances show her wide range and her lyrics are poetic, emotionally charged, and moving. And one other thing, TR Kelley was diagnosed with Autism, or more specifically Asperger's Syndrome.

She was diagnosed late in life, and as a result was able to give a name to her "lifelong oddnesses". She has used this information to become an advocate and an ambassador for people with Autism. When she leaves the comfort of "LeisureLand Community", a community of

people with Autism and understanding NTs (neurotypicals), she helped create, she can be seen presenting and performing to increase awareness and understanding of Autism. She recently presented at "Autreat 2006" in Philadelphia. In The Raventones, she has partnered with Randy Hamme whose talent on drums and percussion bring a backbeat that was not present in her solo CDs.

Odd Birds will be found in the folk music section. It starts off with a strong rhythm with a blues rock feeling. TR Kelley's vocals are strong, moving, and at times march in step with the blues foundation, before floating off in their own powerful direction. TR Kelley's vocal range is incredible and she uses it effectively. At times she sounds remarkably similar to Tracy Chapman, and at other times she evokes images of a jazz lounge singer, a southern rocker, and a gospel singer respectively. The middle of the CD migrates into moving riffs and tunings with less rhythmic dominance and a more melodic styling. Here her vocals really stand out and carry the listener on a hypnotic wave. As it gets near the end, *Odd Birds* takes you back to the basics with some more hard core blues rock.

Their latest release is *Starstruck Enterprise*, another folk CD. This album is very similar to their first, but in many ways comes across as more matured and developed. It can also be described as frenetic at times. The music changes direction in surprising and moving ways. The songs on this album seem more exposed, and it feels like TR Kelley has become more comfortable sharing her view of the world. Like its predecessor, this CD starts with grounding bass lines, and familiar rock and blues beats. Then once again it takes a turn where you are floating on a foundation of cosmic sounds, led by vocal melodies through what, at times feels like a space voyage, enhanced by the Star Trek like dialogue in the background. The beat no longer supports you, and you are floating at the mercy of Kelley's vocal talents and manipulations. Occasionally, a familiar beat creeps in, but then the vocals take over again and carry you off on a moving foundation of bass and guitar chords.

Overall these CDs both convey a serious, contemplative mood, dealing with themes of love, life, humanity, pain, struggles, and relationships. It is easy on the ears and stays primarily in the low end of the sound spectrum. The music is moving and powerful. Knowledge of the fact that TR Kelley has Asperger's Syndrome is irrelevant to enjoying and appreciating the quality of this work. Her songs at times hint at her different perspective and her sense of advocacy, such as this excerpt from "Shades of Grey":

Let me think for my self, cause my brain is working. Let me make my own mistakes, at least they will be mine.

How many colors does the rainbow have, and can you see boundaries between them?

In "Hush" a picture of intimate human communication is painted:

words are hard to find they just get lost inside my mind anyway light year skies starry eyes no surprise but I never knew light year skies shine in your star-struck eyes

The Raventones' view of the world provides fertile material for the neurotypical mind and is sure to rearrange a few neurons for any listener. Whether or not you are familiar with T.R. Kelley's earlier work, you will probably find these CDs enjoyable. Give them a try.

**Kevin Dierks** has been working professionally helping people for over 20 years. He has worked assisting and supporting people with developmental disabilities for most of this time. Through this work he has been taught many things by people with disabilities, and has developed a personal philosophy and professional approach of partnering with people and communities to identify life solutions, options, and actions. He currently works for the Hawaii Department of Health/ Developmental Disabilities Division where he supports innovative approaches and systems changes in an environment of continual improvement in the quality of life for people with developmental disabilities.

#### **Music Review**

**Title:** The Great Escape

**Artist:** Peter Leidy

**Cost:** \$12.00, USD

**Contact:** peterleidy@yahoo.com

610 Miller Ave Madison, WI 53704

Website: http://www.peterleidy.com

**Reviewer:** Steven E. Brown

This is the third human services CD from singer-songwriter Peter Leidy of Madison, Wisconsin. The first two discs, *Greetings from Human Serviceland* and *More Songs for People Like You & Me*, are also available for the same price. For my taste, though, *The Great Escape* is easily the best of the bunch. Leidy's unmistakable style, which includes using the music of many popular songs with his own lyrics, won me, and several of my colleagues, over, as we listened to *The Great Escape*'s title song, which narrates a story of freedom from an institution; "Ride on the Wild Side," about the vagaries and mysteries of paratransit; the Ramones' "Don't Wanna Be Sedated;" and 10 other tunes.

"The Biter" is about a particularly difficult client and "Get This Crap Away from Me" is a literal exposition of some aspects of human services. My favorite is "I Went to a Conference," which explores, in a short song, every aspect of conferences one wants to avoid, and would be a great guide for every conference planner to learn.

Some of the songs I found less interesting have to do with bureaucracy, like "My Friend HIPPA," and "Shred Faster—The Auditors are Coming."

The CD concludes with the serious and gospel-tinged "Coming Home," which expresses the seriousness of the situations that most of the other songs deal with via humor:

I'm coming home
I'm coming home
Coming home
And you know it's been a
Long, long while.
Coming home
When I come home
Well, you know
I'll be wearing a smile.

I'm coming home I've been gone way too long Coming home and soon I will be free I'm coming home Coming home Home where I belong Community is waiting for me. I'm coming home Coming home I'm coming home Home to a real neighborhood I'm going live Gonna live In a home of my own Coming home And Lord I'm feeling good.

This is a worthwhile collection to any disability studies and culture library or archive.

#### **RDS** Information

#### Information for Advertisers

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

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

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

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

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally

sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

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