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# Journal of Postsecondary Education and Disability Volume 23, Number 1 - 2010

SPECIAL ISSUE: **Disability Studies** 

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DISABILITY •

Volume 23, Number

• 2010 • Pages 1 - 92



Association on Higher Education And Disability<sup>®</sup>

# Journal of Postsecondary Education and Disability

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# FROM THE SPECIAL ISSUE EDITOR Sue Kroeger University of Arizona

Over the years, disability rights advocates have scored significant victories. The most notable, the passage of the Americans With Disabilities Act (ADA) of 1990, and most recently, the ADA Amendments Act (ADAAA) of 2008. Additionally, alongside the political movement, we have seen the emergence of disability studies, which now sets the pace for developing new representations of disability.

This relatively new area of academic inquiry reframes the analysis of disability by focusing on it as a social construct and on the conditions that produce disability: the social, political, economic, medical, and legal systems that create barriers for disabled people. This shift in thinking is profound and not easy in light of how deeply disabled and nondisabled people<sup>1</sup> have been socialized to think of disability.

Society's view of disability is pervasive and consistent across language, media portrayals of disability, educational curriculum, human services, and environmental design. It clearly locates the problem of disability within the individual and sees this problem stemming from physical, sensory, emotional, or cognitive limitations.

Disability activists and scholars continue to reject this view and have developed a conceptualization that locates the problem of disability within society. They proclaim that it is not individual limitations or biological differences that are the primary cause of the problem, but society's failure to value and appreciate disability and design environments that are welcoming and inclusive.

Unfortunately, the disability service industry, including disability services (DS) in higher education, generally has not engaged in any consistent and meaningful way with disability studies. Indeed, it is the service industry and we the professional service providers, that help maintain the very frame that scholars and activists are working so hard to change. Operating within a legal narrative and a deficit frame of disability, most DS offices are unaware of the underlying negative messages about disability that they send. This is confirmed for me in talking with colleagues, attending AHEAD's national conferences, reading listservs, and perusing DS Websites. It is my hunch that most service providers have not taken the time to identify the values and beliefs they have about disability and how those values and beliefs guide their work. Moreover, individuals working in DS offices have little academic experiences that would provide them the opportunity to frame disability in a progressive way, with the majority of us coming from such disciplines as special education, rehabilitation, social work, and counseling.

Because we typically and mostly without thinking, frame disability as abnormal, negative, and an individual problem, then it follows that our response to it would be reactive rather than proactive. In other words, we accommodate disability. While this is an improvement over institutionalization, sterilization, and euthanasia, accommodations as a comprehensive response maintains the notion that access is a disabled individual's problem to solve.

On most college and university campuses, disabled students spend an inordinate amount of time establishing eligibility and requesting accommodations. Additionally, they are asked to perform a number of tasks to both schedule and receive accommodations. Oftentimes the rationale for this is self-determination and/or selfadvocacy. While it is important for *all* students to learn to be responsible and assertive, identify issues, solve problems, and make decisions, why should disabled students be required to take responsibility for those access issues that are institutional problems? Why should the academic experience for disabled students be so different from their nondisabled peers?

This special issue is designed to introduce or re-connect practitioners with disability studies and initiate concerted application of disability studies' philosophical foundations to the service arena. Included are six articles (each followed by a professional perspective), two practice briefs, and two book reviews. The professional perspectives are

<sup>1</sup> The descriptors "disabled people" and "nondisabled people" are primarily used in this issue, since disability studies scholars and disability rights activists generally prefer these terms. To understand the rationale for this choice, please refer to *Claiming Disability* (Linton, 1998) and *Controversial Issues in a Disabling Society* Swain, (French, & Cameron, 2003).

intended to be additive and assist the practitioner in application. Ward Newmeyer, Amanda Kraus, Teresa Havens, Katheryne Staeger-Wilson, and Carol Funckes all graciously agreed to write these perspectives and have offered some real pearls of wisdom.

The issue begins with "The Social Justice Perspective" by Gladys Loewen and William Pollard, who introduce us to the philosophical constructs that guide the disability rights movement and the important role that service providers must play in ensuring systemic change.

This is followed by an article by Michael Rembis who provides a historical account of the rise of international disability rights and disability studies. He also helps us to understand the complexity of incorporating the social model of disability into practice.

Rebecca Cory, Julia White, and Zosha Stuckey present a case study in how disability studies theory informed campus thinking about disability. They offer application recommendations to service providers.

Ann Fox's essay on "cripping the classroom" is an engaging essay on incorporating disability studies into campus community life. Her purpose, as she describes it, is to "blur the divide between disabled and nondisabled and to multistream rather than mainstream."

The next article by Alberto Guzman and Fabricio Balcazar presents a quantitative study analyzing the disability perspectives held by service providers in higher education. Informed by disability studies scholarship, the study identifies the thinking behind service delivery policies and practices and provides a framework for future research and professional development. Finally, Susan Gabel discusses social model thinking and presents a project that applied studies and activism.

Two practice briefs, one by Melanie Thornton and Sharon Downs and another by Alan Strauss, offer wonderful examples of efforts that practitioners have engaged in that support and are consistent with the foundations of disability studies.

While there are hundreds of disability studies articles and books that disability service providers would find interesting and engaging, two recent publications were chosen for this issue. Irene Carter's review of Universal Design in Higher Education: From Principles to Practice, and Marcy Epstein's review of Disability and the Politics of Education: An International Reader help to provide a starting point. Additionally, I included two appendices: a selective list of readings, organizations, and Websites; as well as Disability Studies' Guidelines as outlined by the Society for Disability Studies.

Reframing disability and applying this new frame is a great challenge. The field of disability studies provides us with the scholarship, but it is we, the professionals, that must find ways to apply it. That will require us to think and act differently, both personally and in our professional practices. While we may not be able to mandate large systemic change, we can initiate small steps. How do we represent and frame disability on our Websites, in our awareness programs, in our job titles and descriptions, and in our mission statements? While disability studies challenges us to alleviate the need for individual accommodations, how can we deliver them in ways that are consistent with new thinking? Over time, I'm optimistic that these small, but relevant changes will contribute to a new and more progressive disability frame.

# About the Guest Editor

Sue Kroeger, Ed.D. has been Director of Disability Resources at the University of Arizona since 1999. Prior to that she had been Director of Disability Services at the University of Minnesota for fourteen years. She received her master's degree in rehabilitation counseling at the University of Arizona and her doctorate in human rehabilitative services at the University of Northern Colorado. Prior to coming to higher education she worked in public and private rehabilitation.

Dr. Kroeger, in addition to her administrative duties, has presented at numerous conferences, published articles on disability and higher education, and coedited *Responding to Disability Issues in Student Affairs*. She has been Treasurer and President of the National Association of Higher Education and Disability. She holds adjunct faculty status in the Department of Rehabilitation where she teaches undergraduate courses in Disability Studies and advises graduate students. She has been principal investigator for numerous federal grants and has consulted nationally and internationally.

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# The Social Justice Perspective

# Gladys Loewen University of Arkansas Little Rock

# William Pollard University of Massachusetts Boston

## Abstract

This article shines an important light on the continuing struggle of disabled people for dignity, citizenship rights, and access to the marketplace. Common threads bind the struggle for basic human rights among disenfranchised groups, offer experience and approaches to facilitate change, and move society towards social justice. The philosophy behind the Disability Rights movement offers disability service professionals the opportunity to reframe disability in order to effectively advocate for and facilitate social changes in higher education. Disability service professionals have an important role and crucial responsibility in moving their profession, students, and the campus towards a social justice model, supporting disability pride, offering equality, and promoting participatory democracy to disabled students.

"Blind man breakin' out of a trance Puts both his hands in the pockets of chance Hopin' to find one circumstance Of dignity" (Dylan, 1994)

Striving for dignity is at the core of social justice movements. Activists involved in social justice movements believe that oppressed people have a right to fair treatment and a share of the benefits of society based on their human rights and equality of all people (Longmore, 2003; Miller, 2001; Waddington & Diller, 2000), and the principles of participatory democracy (Weisman, 1999). This article will review the history of the Disability Rights movement within a social justice perspective and reflect on the implications this movement has on the disability service (DS) profession and the delivery of services to disabled students in higher education.

Social justice movements have struggled and continue to struggle with issues such as sexism, racism, heterosexism, ageism, ableism, and classism (Johnson, 2006). The Women's movement opposes oppression from violence and harassment, and works for equal wages as well as reproductive and voting rights (Eisenberg & Ruthsdotter, 1998; Epstein, 2002; Hugemark & Roman, 2002; Jones, 2008). Vietnam War Veterans advocated for medical, educational, and disability benefits (Madaus, Miller, & Vance, 2009); Veterans of the Gulf War and the Iraq invasion are fighting to get recognition and understanding for the debilitating, emotional trauma experienced in current approaches to war (Church, 2009; Madaus, Miller, & Vance, 2009; Shackelford, 2009). The Gay and Lesbian movement's priority is acceptance and dignity, full inclusion in society with marriage rights, and access to benefits for partners (Gianoulis, 2004; Johnson & Summers, 2004; Nedeau, 2008). Through the Civil Rights movement, African Americans fight for racial dignity, respect, economic and social equality, and freedom from white domination (Microsoft Encarta Online Encyclopedia, 2009; National Park Service [NPS], n.d; Ruehl, 2009; Teaching Tolerance, 2009).

"I know one thing we did right Was the day we started to fight Keep your eyes on the prize, hold on (hold on) Keep your eyes on the prize, hold on" (as cited in Marsh, 2009)

Alice Wine wrote this song after African Americans had won the right to vote, only to discover one more

barrier; they were required to pass a literacy test in order to qualify to vote. Songs of hope and empowerment were influential during the Civil Rights movement as they identified the common goal worth fighting for and offered optimism that the prize was achievable (Marsh, 2009; Ruehl, 2009).

All these social justice movements have made gains to varying degrees in achieving their goals related to social justice (Crow, 1996). African Americans and women won the right to vote (Eisenberg & Ruthsdotter, 1998; Microsoft Encarta Online Encyclopedia, 2009) as well as equal pay for equal work (Eisenberg & Ruthsdotter, 1998); women won reproductive rights with Roe vs. Wade (Eisenberg & Ruthsdotter, 1998; Nedeau, 2008). Several American states as well as countries such as Canada have passed legislation granting same-sex couples the right to marry (Gianoulis, 2004; Johnson & Summers, 2004; Jones, 2009.). Post traumatic stress disorder (PTSD) is now a recognized outcome of war (Church, 2009). These movements have worked hard to remove the barriers caused by privilege, which "... exists when one group has something of value that is denied to others simply because of the groups they belong to, rather than because of anything that they've done or failed to do" (Johnson, 2006, p. 21).

As a result of these gains, the Disability Rights and Gay Rights movements (Jones, 2009) were able to utilize those experiences, strategies, and perspectives in order to enhance their own struggle towards achieving social justice and empowerment in several ways (Crow, 1996; Madaus, 2000; Malhotra, 2001; Waddington & Diller, 2000). Activists realized that issues of physical access and attitudinal barriers could now be described as a socio-political problem (DeJong, 1983; Waddington & Diller, 2000). They also gained awareness that social programs, segregated education and housing programs, and employment quotas, inspired by a social welfare model (Hugemark & Roman, 2002; Marks, 2008; Waddington & Diller, 2000), lead to "social exclusion" (End Exclusion, 2007). Disability activists and scholars also recognized that social welfare models rely on a functional definition to qualify for services that can segregate those who are eligible, which further marginalizes the members of society who qualify for this service (Hugemark & Roman, 2002; Waddington & Diller, 2000). And lastly, they recognized that social welfare models require people to disclose their inabilities or limitations in order to gain access to special services (Shakespeare, 1996; Waddington & Diller, 2000). This disclosure in

turn reinforces the stereotypes about the incompetence of people who require special support (Hugemark & Roman, 2002; Linton, 1998; Longmore, 2003).

It is not an easy task to change a history of attitudes, behaviors, laws, and social policy that allow for discrimination and marginalization of a segment in our society. The struggle for equal rights now involves multiple racial groups such as Latinos and Asians (Teaching Tolerance, 2009) as well as the issues of rights based upon gender, disability, and sexual orientation (Hugemark & Roman, 2002; Malhotra, 2001; NPS, n.d.; Shakespeare, 1996). Members involved in a social cause need to keep an eye on the prize and persist in pressing for change as personal, social, and economic costs of exclusion and marginalization are too high to be ignored (End Exclusion, 2007; Hugemark & Roman, 2002; Linton, 1998; Shakespeare, 1996).

### **Disability Rights Movement**

"There is a Third Kingdom the land of the crippled. This place is no democracy; it is a dictatorship. The usual rights of citizenship do not apply here. A great wall surrounds this place, and most of what goes on within the wall is unknown to those outside it" (Gallagher, 1990. p.1).

The focus of the Disability Rights movement has been to change the way the world is constructed so that everyone can participate in life's activities to the greatest extent possible with maximum independence (Longmore, 2003; Malhotra, 2001; Weisman, 1999; Winter, 2003). This movement has similar goals as the Civil Rights movement—to be treated with respect and dignity, have economic and social equality, experience usable and inclusive environments, and have the opportunity for full participation (UPAIS, 1976) in educational, employment, and community activities (Malhotra, 2001;Winter, 2003).

Throughout modern times in North America and parts of Western Europe, disability-specific groups have formed to champion specific interests with a focus to solve specific disability issues, not global issues. Examples include (Fleischer & Zames, 2001; Malhotra, 2001; Pullingart, 2002; Resource Center for Independent Living, 2004):

1921 - American Foundation for the Blind1938 - March of Dimes as the National Founda-

tion for Infantile Paralysis

- 1939 League of the Physically Handicapped
- 1940 National Federation of the Blind
- 1948 National Spinal Cord Injury Association
- 1950 National Association for Retarded Citizens
- 1974 People First Canada group began in British Columbia
- 1975 Union of Physically Impaired Against Segregation (UPIAS) founded in Britain

In the 1970s, disabled activists and scholars from Great Britain, such as Ken Davis, Paul Hunt, and Vic Finkelstein (UPIAS, 1976) and the United States, such as Judy Huemann, Ed Roberts, Fred Fay, and Justin Dart (Fleischer & Zames, 2001; Pelka, 1997) started to question and voice opposition to society's response to various aspects of disability. In 1974, some of these activists, understanding the importance and the power of cross-disability communication and cooperation, came together in Washington, D.C. to propose a crossdisability coalition (Pelka, 1997). The American Coalition of Citizens with Disabilities (ACCD) was formed and initially brought 19 disability groups together for a common purpose of promoting disability inclusion (Pelka, 1997). The ACCD was led by the late Frank Bowe, a deaf activist and educator who, as its first Director, worked diligently to support the passage of the Rehabilitation Act of 1973 (Fleischer & Zames, 2001) and called for civil disobedience to bring pressure on the Carter administration to approve the regulations (Pelka, 1997). In 1977, at the local level, activists such as Irv Zola, Marsh Saxton, David Pfieiffer as well as former AHSSPPE member Andrea Schein (Pelka, 1997) and other local activists, formed Boston Self-Help, a grassroots peer counseling and cross-disability organization.

International activity was also prevalent. In Canada, the Coalition of Provincial Organizations of the Handicapped (COPOH) was founded in 1976 by people with disabilities and in 1994 they changed their name to the Council of Canadians with Disabilities (CCD) (Pullingart, 2002). The CCD remains focused on civil rights issues with the motto, "A voice of our own" (Canadian Council on Disabilities [CCD], 2009). A 1982 amendment to the Canadian Charter of Rights and Freedoms made Canada one of the few nations in which non-discrimination on the basis of disability became a constitutional right (Waddington & Diller, 2000). At the statutory level, the Canadian Human Rights Act has prohibited disability discrimination since 1985 (Barnartt, 2008; Rogow, 2002). A Disability Discrimination Act was passed in Australia in 1992, and in Great Britain in 1995 (Waddington & Diller, 2000); both pieces of legislation focus on systemic discrimination, bringing social justice to the forefront, and removing the emphasis on social welfare approaches.

The fight for social justice for many disabled people is not merely a political one, but also a lived philosophy that reflects years of struggle and personal growth (Crow, 1996; Linton, 1998; Shakespeare, 1996). With this growth, struggle, and knowledge comes a clear understanding that what is shared by disabled people is far greater than physical difference; they share oppression, not just impairment (Crow, 1996; Longmore, 2003; UPIAS, 1975). As Miller (2001) states: "...of course social justice has always been, and must always be, a critical idea, one that challenges us to reform our institutions and practices in the name of greater fairness" (p. x). The Disability Rights movement is challenging society to change its treatment of disabled people in the interest of fairness and equal rights.

Johnson (2006) contends that the systems and structures established by society are the main source of discrimination where privilege is exercised to maintain traditional systems and social patterns in order to keep the status quo. While individuals may exhibit some form of exclusion through their actions (racism, sexism, ableism, etc.), these individuals are part of systems or structures that support their actions, making discrimination a systemic issue (Hugemark & Roman, 2002). "As with gender, race, sexuality and class: to understand how disability operates is to understand what it is to be fully human" (Garland-Thomson, 2006, p. 271).

Longmore (2003) suggests that the "implementation of the medical model in health care, social services, education, private charity and public policies has institutionalized prejudice and discrimination" (n.p.). This perspective is supported by Shakespeare (1996) who states that we "are socialized into thinking of disability in a medical model way. We can view this as internalized oppression" (p.106). Thus, disability is viewed in a negative way, maintaining discriminatory practices. These oppressive views and approaches to disability gave rise to the Disability Rights movement.

## **Civil Disobedience to Reduce Discrimination**

"If the change in paradigm that the disabled seek is to come about, it will only be through active and vocal protest by the disabled themselves, and their insistence that there is more to disability than malfunctioning body parts, and more to being disabled than meets the eye." (Eisenberg, Griggins, & Duval, 1982, p. xix)

The Civil Rights movement has had an effect not only on securing certain rights, but also in the manner in which those rights have been secured (Madaus, 2000). When traditional legal channels were exhausted, disabled persons learned to employ other techniques of social protest, such as demonstrations and sit-ins, learning from the Civil Rights movement (Barnartt, 2008; DeJong, 1983; Fleischer & Zames, 2001; Shakespeare, 1996). Linton (1998) suggests that because disabled people are "bound by common social and political experience," they could use this common identity "to function as a basis for political activism" (p. 12) in order to increase their ability to participate in society.

Despite changes in legislation, disabled people continued to experience discrimination and exclusion. They began expressing their frustration and anger, leading to protests and civil disobedience in order to demand their civil rights (Fleischer & Zames, 2001; Malhotra, 2001) and bring attention to discriminatory practices (Barnartt, 2008; Shakespeare, 1996). Sample protests include (Barnartt, 2008; Fleischer & Zames, 2001; Malhotra, 2001; Resource Center for Independent Living, 2004):

- 1939 The League of the Physically Handicapped protested at The Home Relief Bureau of New York City which was supposed to forward their job requests to the WPA, but was stamping all their applications 'PH' for physically handicapped, as a signal to the WPA not to give these people jobs.
- 1978 Atlantis Community, founded by Wade Blank, staged a sit-in demonstration to protest the complete inaccessibility of Denver's mass transit system. Up until this time, the city refused to purchase wheelchair lift-equipped buses. Atlantis later became American Disabled for Attendant Programs Today (ADAPT).
- 1986 With pressure from the Paralyzed Veterans of America, the Air Carrier Access Act was passed. Before its passage, airlines could

refuse to serve people simply because they were disabled, and charged them more for airfare than non-disabled travelers.

 1990s - ADAPT fought for reallocation of one quarter of the federal and state Medicaid dollars from institutional programs to consumer controlled community-based programs. Since then, ADAPT has decided the name will no longer be an acronym so it is now simply ADAPT; this organization is still fighting for community services and supports for people with disabilities of all ages, trying to reduce discriminatory practices.

The militant actions of the Disability Rights movement also spread to postsecondary institutions (Fleischer & Zames, 2001) when "new civil rights action began to take root, as exemplified by the work of students at the University of California at Berkeley" (Madaus, 2000, p. 7). This group of students fought for greater independence on campus and ultimately realized increased access through improved transportation options, classroom accessibility, and renovation of curb cuts (Fleischer & Zames, 2001; Madaus, 2000). Their activism paid off, paving the way for disabled students to realize that higher education was within reach.

The Disability Rights movement not only worked to gain respect and full participation in society, but also struggled to find acceptance for disabled people in other social movements (Amundson, 2009; Crow; 1996; Shakespeare, 1996; Triano, 2003). Unfortunately, other social movements excluded disabled individuals as a part of the composition of their individual and collective social justice models (Johnson, 2006; Malhotra, 2001; Shakespeare, 1996). According to Garland-Thomson (2006), "feminist theories all too often do not recognize disabilities in their litanies of identities that reflect the category of women" (p. 257). These movements fought for their own rights and joined others in their fight, but are noticeably absent in their support of the struggle for social justice by disabled people (Amundson 2009; Shakespeare, 1996).

Their exclusion and failure to see the parallels in the battle for acceptance continue to re-enforce the negative effects of people's view of disability. "Positions held by the DR [Disability Rights] movement are summarily rejected by many within the academy, even though similar positions are unquestioningly endorsed when stated by advocates of women's rights and 'racial' or ethnic civil rights" (Amundson, 2009, p. 169).

## A Different View of Disability

"Pride is somewhere in your soul Pride is the peace within that finally makes you whole

Celebrate your difference with pride Pride in yourself is bound to set you free Pride in who you are just a person like me Pride and self respect and gentle dignity No one can take away your pride." (Crescendo, 1993, n.p.)

Activists began to realize that their oppression and marginalization was not only "rooted in the prejudices or misconceptions, but, also, in the good intentions, in the minds of persons without a disability as they are manifest in their interactions with persons with disabilities" (Winter, 2003, p. 3). As a way to address these prejudices and misconceptions, a group of activists from Britain known as the Union of Physically Impaired Against Segregation (UPIAS) introduced a social justice definition of disability in 1975. The UPIAS believed that disability was caused by social institutions, societal beliefs, and attachment to the Medical Model of Disability, sometimes called the Individual Model of Disability (Shakespeare, 1996), which defines disability around functionality and normalcy (UPIAS, 1976). This model infers that disability results from the individual's physical or mental limitations, is a personal problem or tragedy, and is unconnected to the social response or the environment (Crow, 1996; Oliver, 1996; Shakespeare, 1996; Winter, 2003). The disabled person is expected to seek assistance in getting cured, fixed, or accommodated as it is their individual problem to solve in order to be included and participate in society (Crow, 1996; Linton, 1998; Longmore, 2003).

The UPIAS endeavored to change this view of disability by stating that *impairment* was a medical condition or illness and that *disability* was something imposed on top of impairment by the way society isolated and excluded full participation in many situations. Their political charter declared that it wasn't the impairment, but society's attitude towards the impairment that caused the disability.

Thus, we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (UPAIS, 1976, p.14).

This was a pivotal moment in the Disability Rights movement (Crow, 1996; Shakespeare, 1996; Winter, 2003). Several disability scholars built on this new view of disability which later became known as the Social Model of Disability. Gill's (1994) Interactional or Socio-political Model of Disability seems to summarize all the variations and builds on the following premises: disability is a difference; disability in and of itself is neutral; disability derives from the interaction between the individual and society; the remedy to this problem is to change the interaction between the individual and society; the agent of change can be the disabled person, an advocate, or anyone who affects the interaction between the individual and society (Block, Kroeger, & Loewen, 2002). Disability stems from the failure of society to adjust to meet the needs of disabled people.

This model does not deny illness or the need for medical intervention; rather, it offers a lens that brings a clearer understanding of barriers created by society's attitude toward disabled people and how these barriers affect them. It views "negative self-identity as a result of the experience of oppressive social relations, and focuses attention on the possibilities for changing society, empowering disabled people, and promoting a different self-understanding" (Shakespeare, 1996, p. 5) and extends hope for dignity and participation in society. It offers a fresh change from the medical model that considers "negative self-identity to be an outcome of physical impairment, and focus on the need for adjustment, mourning, and coming to terms with loss" (Shakespeare, 1996, p. 5). Table 1 depicts the distinction these activists made between disability and impairment.

This social approach also provides a more personal understanding of the disability experience (Linton, 1998; Oliver, 1989) and offers common ground in the disability community.

My life has two phases: before the social model of disability, and after it. Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it (Crow, 1996, p. 55). Table 1

## Term Comparison

| Term        | Medical Model  | Social Model   |
|-------------|--|--|
| Impairment  | A physical or mental condition,<br>deficit, or limitation that requires<br>treatment or fixing   | Lacking part or all of limb, organ or mechanism of the body  |
| Disability  | The condition of being unable to<br>perform a task due to an<br>impairment which is an<br>individual burden, personal<br>tragedy or individual problem | The disadvantage or restriction of activity<br>caused by design of environments which<br>exclude disabled persons from<br>participation in mainstream social<br>activities     |
| Implication | The individual must adjust or<br>become more normal to fit into<br>society and the established<br>environments   | Society must adapt the design of<br>environments. Individual differences are<br>considered normal and accepted through<br>the design of inclusive and flexible<br>environments |

Disability rights activists and scholars have rejected the Medical Model of Disability and embraced variations of the Social Model of Disability with the perspective that it is society's response to disability that is the real problem which profoundly impacts the lives of disabled people (Shakespeare, 1996). The Disability Rights movement has reassigned "a meaning [to disability] that is consistent with a sociopolitical analysis of disability" (Linton, 1998, p. 10). The growth and development of the social model is a clear reflection on how disabled individuals and disability scholars are engaged in discourse about the interaction of these two powerful forces - disability and society. As a society, we continue to design environments that exclude people with disabilities or limit their participation, leading to oppression, segregation, and negative identity (Crow, 1996; Brown, 2007; Hugemark & Roman, 2002; Shakespeare, 1996; Weisman, 1999; Winter, 2003). This approach parallels the concerns of other racial and ethnic minority groups who believe that if the problem lies within society and the environment, then society and environment must change (Longmore, 2003; Shakespeare, 1996; Winter, 2003).

The focus on the Social Model of Disability has made an impact on the use of language regarding disability (Brown, 1997; Crow, 1996). Initially, society used terms like cripple, handicapped, physically challenged, and wheelchair-bound (Fleischer & Zames, 2001; Linton, 1998). In the late 1970's, society started using "people first" language, person with a disability, as a way to focus on disability as a characteristic of the individual (Linton, 1998). In the mid 1990's, disability activists and scholars made a conscious decision to use the term disabled people. "Rather than maintaining disability as a secondary characteristic, disabled has become a marker of the identity that the individual and group wish to highlight and call attention to" (Linton, 1998, p. 13).

Disability scholars are now promoting a prideful use of disability as a form of claiming this identity within the social model. If disability becomes accepted as part of the diversity of humanity, then it can become a source of pride, a descriptor, and an identity rather than the source of the problem (Crow, 1996, Winter, 2003). Table 2 shows the evolution of the language change that reflects current thinking of disability by disability activists (Linton, 1998).

All of these changes, reformed view of disability and new language, are clearly linked to the natural flow in the development of a minority conscience as people Table 2

| Disubility Dangaage Change |  |  |
|----------------------------|--|--|
| Cripple, Invalid<br>∏      | Person is abnormal and is outside of the norm of society                     |  |
| Handicapped                | Person is abnormal, different, and needs a cure to belong                    |  |
| Person with a Disability   | Person has an abnormality, and with a cure, can belong                       |  |
| Disabled Person            | Person is part of diversity of society, and can be proud of their difference |  |

Disability Language Change

proudly claim disability and the pride of a shared culture in the reframed view of disability. These changes parallel the pride demonstrated by the activists in the Civil Rights, Women's Rights, and Gay Rights movements (Crow; 1996; Epstein, 2002; Hugemark & Roman, 2002; Linton, 1998; Nedeau, 2008; Shakespeare, 1996; Triano, 2003).

#### Implications for the Disability Service Professional

"The world which people have constructed is made by and for nondisabled people; for those who can climb stairs, turn doorknobs, and faucets, see where they are going, hear voices, commit instructions and information to memory. Educational programs reflect these values" (Jastram & McCombs, 1981 p. A-2).

For the most part, twentieth century educational programs were designed for non-disabled people, making it difficult for disabled students to fully participate in higher education. Madaus (2000) documents the history and evolution of DS offices in higher education and reports that most offices were established in response to external forces such as legislation and social justice movements, not through a philosophy of inclusion.

Generally, practices in DS offices in most institutions have developed fairly traditional procedures with 3 major steps: (1) registration and documentation to gain eligibility; (2) letters to, or discussions with, faculty regarding accommodations based on documentation; (3) provision of accommodations within reason, such as changing the educational task, or retrofitting the activity through collaboration between faculty and the DS office to manage the accommodation (Izzo, Murray & Novak, 2008; Ketterlin-Geller & Johnstone, 2006). This process requires disabled students to disclose personal information for the purpose of qualifying for special services (Waddington & Diller, 2000) in order to have the opportunity for increased participation in the classroom (Izzo, Murray & Novak, 2008).

According to a recent study (Guzman, 2009), this accommodation approach to helping disabled students and retrofitting activities through individualized and oftentimes segregated services is driven by the Medical Model of Disability. These individualized adjustments and accommodations tend to "reinforce the individual/medical notion that disability resides with the individual" (Guzman, 2008, para. 5) and focus on individual limitations that promote existing stereotypes of disabled individuals as tragic or inspirational; these stereotypes do not match the disability experience (Linton, 1998). A program based on helping, or taking care of, disabled students can be seen as patronizing (Linton, 1998) and does not necessarily value disability as part of the diversity of society (Harbour, 2009; Hugemark & Roman, 2002).

Recent studies have identified several problems

with the accommodation model of supporting disabled students. Students can feel humiliated and stigmatized by having to disclose disability information and request special treatment in order to participate in campus activities (Field, Sarver, & Shaw, 2003; Izzo, Murray & Novak, 2008; Ketterlin-Geller & Johnstone, 2006). Students and DS providers report that equal access to classroom participation, including reasonable accommodations, remains an issue (Burgstahler & Moore, 2009; Acosta, 2007; Izzo, Murray & Novak, 2008; Ketterlin-Geller & Johnstone, 2006). Faculty identify that it can be time consuming and difficult to find ways to retrofit the course activities or modify them after the fact (Ketterlin-Geller & Johnstone, 2006); in some cases faculty are unaware of their responsibility to provide accommodations (Burgstahler & Moore, 2009) or are unaware of the strategies to include disabled students (Harbour, 2009). Disability Service providers often end up playing the role of mediator between faculty and students, creating a dependency from faculty and students (Izzo, Murray, & Novak, 2008). This dependency discourages students from negotiating their own solutions directly with instructors and exercising self-empowerment (Shaw, 2002), and hinders instructors from developing their own solutions to create an inclusive environment.

Guzman's (2009) survey of DS providers reports that over 75% of DS staff concentrate on compliance rather than a social definition of disability to determine "When disability is viewed eligibility for services. through the lens of compliance, the focus is often placed on 'what must be done' rather than 'what can be done'" (Project Pace, 2009, n.p.). This legal focus by service professionals coupled with the practice of retrofitting course activities and recommending accommodations does not appear to ensure full participation of disabled persons in postsecondary education (Guzman, 2009; Ketterlin-Geller, & Johnstone, 2006; McGuire & Scott, 2006; Izzo, Murray, & Novak, 2008). As Oliver (1996) states: "Integration is not a thing that can be delivered by politician, policy makers or educators, but a process of struggle that has to be joined" (p. 90).

According to Marks (2008), a social justice approach is not universally used or applied in higher education.

...many US colleges and universities adhere to a different framework, the social welfare model of DS. The social welfare model regards people with disabilities as the objects of philanthropy, charity

and good will. Social welfare models stress 'needs' rather than rights. Consequently, the social welfare model tends to take care of people, but it treats people with disabilities as less than equal and with paternalism (Marks, 2008, para. 12).

When one considers the Disability Rights movement and the struggle to achieve social justice, it seems that DS professionals have not embraced the goals of this movement, nor understand that they might play a role in maintaining a system that discriminates against disabled people and hinders their goal to achieve social justice. Their current approach to disability supports and policies can actually hinder the opportunity to achieve social justice as the services create an illusion of independence and equal opportunity for the person receiving special services (Brown, 2001). As long as institutions persist in designing environments that limit full participation, service provision will continue to be offered on a special basis as a retrofit, continuing the social welfare approach (Longmore, 2003).

This tactic emphasizes the differences in minority students rather than how the campus needs to improve and change in order to accept disability as part of the diversity of the campus (Harbour, 2009). Achieving full participation requires a change from a social welfare model to a social justice model with an emphasis on ethics and values as a way to reduce discrimination and academic barriers. "Restrictive environments and disabling barriers," part of the "systemic deprivation" (Oliver, 1996, p. 75) experienced by disabled people, lead to continued discrimination and exclusion from society's activities.

#### Recommendations

The principles of non-discrimination, equal opportunity, and personal empowerment are fundamental in meeting the goals of the DS profession—ensuring full participation of persons with disabilities in higher education (Association on Higher Education And Disability [AHEAD], 2009). If the goal is full participation in higher education, then efforts from DS professionals compel others to find ways to ensure that all individuals are entitled to equal participation and not view any services as special or extraordinary when they are given to disabled students due to poorly designed environments (Marks 2008; Waddington & Diller, 2000). Exploring ways to include people with disabilities in all environments rather than maintain a parallel track (Guzman, 2009) leads to the promotion of environments that are inclusive, minimizing the need for retrofitting and different treatment (McGuire & Scott, 2006; Rose & Meyer, 2002). It is also important to lessen the emphasis on documentation and labeling that leads to discrimination and segregation with special treatment (Waddington & Diller, 2000; Longmore, 2003). Accommodations should be viewed as a social problem due to poor design and discrimination (Longmore, 2003) with the right to full participation, not a privilege based on documentation. This entails a shift from accommodations as a primary focus to strategies that minimize the need for accommodations (Burgstahler & Moore, 2009) as the guiding principal.

McGuire and Scott (2006) state "the time has come to move the paradigm relating to instructional access from accommodation to full inclusion." Inclusive or universal design (Izzo, Murray, & Novak, 2008; McGuire & Scott, 2006; Rose & Meyer, 2002) is the best method for advancing social justice for the disabled persons in our campus communities. Weisman (1999) suggests that a focus on the spirit of the law rather than the letter of the law provides a way to create a systemic change in attitudes and behaviors within institutional structures in order to achieve full inclusion and participatory democracy.

Service professionals must explore a more enlightened view of disability and social justice in their work. If the movement towards social justice and the strengthening of community and culture are still for the most part elusive to the disabled students they serve, it is incumbent on service professionals to develop strategies which will educate and inform the campus community, including students, that full participation is a right, not a privilege. Encouraging all members of the campus to take responsibility for full inclusion of all constituents (Block, Loewen, & Kroeger, 2006) is a healthy response to accepting the diversity of the campus population (Harbour, 2009).

Laws and policy cannot be the only answer; therefore, as service professionals, we must continue to champion disability as ordinary, respectable, and positive (Marks, 2008), not special.

Disability can be understood as something natural, and disability identity can open doors. People with disabilities choose how they feel about disability, and disability support professionals should do all we can to develop disability identity in its most positive context (Marks, 2008, para. 29).

Disability Studies scholars advocate for activities

that celebrate the rich history and culture of the Disability Rights movement and personal voices of disabled writers, artists and musicians (Linton, 1998; Longmore, 2003) to replace the traditional disability awareness activities which do not focus on the rights of disabled students nor the richness of the disability culture and the disability experience. Service professionals could also collaborate with other disciplines to design Disability Studies courses/programs and examine how disability is portrayed in other academic areas such as Social Sciences, Medicine, and Education (Linton, 1998). The purpose would be to educate departments and the campus community to focus on a view of disability that is consistent with current research on disability and social justice, which Amundson (2009) strongly suggests is a missing piece of the campus discourse. "I will argue, discourse that defends the justice of socially inflicted disadvantage to people with impairments is not only accepted within the academy—it is virtually the norm" (p. 169).

As members of the academic community, DS professionals have the opportunity and the responsibility to engage faculty and senior administrators using Disability Studies as a form of political action and academic inquiry. This dialogue will provide the catalyst to inform and mobilize both disabled and non-disabled people, to develop allies among other disenfranchised groups, and explore the similarities in the struggle to achieve social justice. Coalitions are more effective than individual efforts as they offer the opportunity to develop stronger public support and increase visibility (Bystydzienski & Schacht, 2001) and awareness for social justice issues in our profession.

## Conclusion

"...prejudice is a far greater problem than any impairment: discrimination is a bigger obstacle for them to 'overcome' than any disability" (Longmore, 2003, n.p.).

The challenge facing the DS profession is changing policies and practices so they are guided by a social justice model of disability in order to be consistent with the thinking of disability scholars and activists (Amundson, 2009; Guzman, 2009; Marks 2008). The DS profession has at times been forced to view and interpret the law in too narrow a fashion and not as it was intended as civil rights legislation (Brown, 2007; Fleischer & Zames, 2001; Scotch, 1984). Guzman (2008) purports that while some DS professionals:

will lack the support, tools and/or resources to provide other than individual accommodations, it is important to understand that in many situations complying with required minimums promotes the segregation, limited participation and unequal access of students with disabilities and, therefore, maintains a discriminatory environment which runs against the spirit of what legislations such as the ADA intended (para. 5).

Many service providers have started the process of changing their approach and understanding of disability but have yet to view full participation as a civil rights issue. They "often rely too heavily on environmental solutions" (Marks, 2008, n.p.) instead of focusing on equality and social justice. Public policy and societal perceptions regarding disability generally focus on costs to offer services, not on human rights for those who experience discrimination and exclusion (Longmore, 2003). Postsecondary institutions often do not provide per capita funding for disability resources and with the increasing numbers of disabled students (Henderson, 2001), resources and supports become thin. Limited budgetary allocations have an impact on potential decisions and solutions for bringing about change (National Council on Disability, 2003).

Treating disabled people as if they were invisible, designing buildings as if everyone was nondisabled, seeing people with disabilities as inferior or abnormal... all these aspects of their oppression enable nondisabled people to deny a basic truth of the human condition (Johnson, 2006. p. viii).

Disability Service professionals must make a paradigm shift in attitude and action that moves disability into a social movement resulting in full inclusion in all aspects of community life. "Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties; it was external factors, the barriers constructed by the society in which I live" (Crow, 1996, p. 55). Once this switch to viewing inclusion as a social justice issue is achieved, we will create an opportunity for disabled persons to embrace a clear and prideful identity and have a greater chance to realize participatory democracy (Weisman, 1999) in higher education with maximum independence. Disability Service professionals must increase individual and collective efforts to educate students, the campus community, and other disenfranchised groups that disability is not an isolated issue of social welfare,

but must and should be acknowledged as a struggle for human dignity, non-discrimination, equal opportunity, and personal empowerment through independence. This involves changing the focus from individual accommodations to removal of the barriers in our institutions and everyday life (Block et al., 2006). "...the true sign of success is not whether we are a source of perpetual aid that helps people scrape by -- it's whether we are partners in building the capacity for transformational change" (Obama, 2009).

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# **About the Authors**

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# **Professional Perspective**

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Imagine if you will, a university where women or students of color are required to self-identify, provide documentation, and be made eligible to obtain textbooks, take exams, utilize technology, or participate in field trips. We would consider such an institution to be absurd and discriminatory in their attitudes and actions. So why, given the knowledge and technology we have available to us today, do we continue to require similar actions from disabled students?

In "The Social Justice Perspective" Gladys Loewen and William Pollard guide readers through key details of the Social Justice Movement and its applications within the field of disability services. They begin with a brief history and move through the Disability Rights Movement, medical model, and social welfare perspectives, and then continue with examples and parallels from other civil rights movements. We are reminded that, just as in other campaigns for civil rights, the problem lies with society and the environment, rather than with individuals; society and the environment need to change in order to include everyone. These examples help demonstrate the more just and equitable standards the social justice perspective offers and give practitioners "the opportunity to reframe disability in order to create social changes in higher education." The importance of re-evaluating our current assumptions, beliefs, practices, and procedures as disability service professionals is brought to the forefront. We are challenged to increase our efforts to remove barriers throughout our institutions and to infuse disability into our campus diversity efforts.

# Yes We Can Change: Disability Studies -Enabling Equality

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#### Abstract

In this article, I offer a brief assessment of the international disability rights and culture movements and disability studies, as well as a commentary on the future of disability and disability studies. A diverse group of activists, artists, and scholars have brought about momentous legal changes in dozens of countries around the world. They have also enabled a critical rearticulation of what it means to be disabled. Yet, this revisioning of disability and this repositioning of disabled people remains fraught. I contend that while movement participants, scholars, and their allies are off to a great start, they have yet to grapple in any serious way with some of the most important and contentious issues within the disability rights and culture movements and disability studies, namely their own internal diversity and the material reality of many disabled peoples' lives. Despite these complexities, I maintain that the disability rights and culture movements and disability studies have tremendous transformative potential.

We are living at a critical moment of history. The election of Barack Obama as the 44<sup>th</sup> President of the United States on November 4, 2008 was greeted the world over with a potent mixture of unrestrained joy and hope by those individuals, groups, and organizations who rallied around his campaign slogan, "Yes we can change" (Obama, 2008b). Especially moved were people of color, people with disabilities, and women; people who have historically been excluded both structurally and culturally from power.

When President-elect Obama delivered his victory speech to the more than one million people crammed into Chicago's Grant Park and millions more watching around the world, he directly acknowledged his constituency, the "young and old, rich and poor, Democrat and Republican, black, white, Hispanic, Asian, Native American, gay, straight, disabled and not disabled," who welcomed new possibilities, supported democracy, and believed that their voices could make a difference in the future of the United States and the world (Obama, 2008a).

For those of us active in the disability rights and culture movements and disability studies, Obama's victory speech was truly an historic event. Though the most politicized among us balked at Obama's choice of words (the "disabled"—as if we were some immutable monolith), we recognized that we, the disabled, had arrived socially and politically. Or had we?

In this article, I will offer a brief assessment of the recent past and a commentary on the future of disability and disability studies. I will highlight the major legal and theoretical contributions that a diverse group of activists, artists, and scholars have made in opening the world to people with disabilities, and I will show that despite momentous achievements in many areas, much work remains to be done. By forcing legislators, administrators and academics, architects and building contractors, city planners and business owners, to allow equal access, the disability rights and culture movements and disability studies have made people with a broad range of disabilities an increasingly salient minority. Activists, artists, and academics have also enabled a critical rearticulation of what it means to be disabled.

We are seeing in K-12 and post-secondary education, in the media, and in our everyday lives, the tremendous potential that this new access and this new understanding of disability hold. Yet, this re-articulation of disability and this repositioning of disabled people remain contentious and incomplete. While we are off to a great start, those of us closest to the movement and to disability studies have fallen short in our attempts to contend with some of the most important issues within the disability rights and culture movements and disability studies, namely our own diversity and the material reality of many of our lives.

## Activists, Artists, and Scholars

In this first section, I will provide a brief historical account of the rise of the international disability rights and culture movements and disability studies. All three movements emerged roughly at the same time and were very much interrelated. They, moreover, are the reason why President-elect Obama included disabled people in his victory speech.

Disabled people and their allies have been active socially and politically for well over one hundred years. Recent scholarship (Burch, 2001; Kudlick, 2001; Longmore, 2003) has shown that in the United States for example, both blind people and deaf people have been actively building and defending their own cultures and communities since at least the turn of the twentieth century. Longmore (2003, p. 105), moreover, has argued that by the mid-twentieth century, the National Federation of the Blind (NFB) had a "vigorous" lobby in Washington that took a "consistent" civil rights approach to disability issues. Parents and other allies of cognitively disabled and learning disabled individuals have also been active in gaining and protecting their civil rights and their access to education, employment, and community living for decades (Noll & Trent, 2004). Yet, scholars agree that the modern disability rights movement, which in most countries consists of a broad cross-section of the disabled population and highlights a politicized disabled identity, emerged out of the social turmoil and civil rights struggles of the 1960s and 1970s.

Initially based primarily in the United States and the United Kingdom, the modern disability rights movement focused largely on access, accommodation, and independent living (Barton & Oliver, 1997; Campbell & Oliver, 1996; Charlton, 2000; Fleischer & Zames, 2000; Hahn, 2002; Oliver, 1996: Shapiro, 1994; Switzer, 2003). Throughout the 1970s, numerous disability rights groups emerged in other parts of Europe, and in New Zealand, Australia, Latin America, and southern Africa as well. Although they never lost sight of their original goals, by the early 1980s, disability rights organizations in various parts of the world became increasingly involved in broader global human rights struggles and national liberation movements (Charlton, 2000).

Prodded by movement participants and its member states, the United Nations (UN), in many ways, became a global standard bearer for disability rights. Though it remained focused largely on the rehabilitation and reintegration of so-called productive disabled people, especially those living in the "developing world," by the early 1970s the UN began to advocate for the rights of people with disabilities. According to the UN's own history, it began during the 1960s to recognize an increasing awareness of the importance of new rehabilitation strategies (United Nations, 2003-04a). On December 20, 1971, the UN General Assembly introduced the Declaration on the Rights of Mentally Retarded Persons and called for national and international action to ensure that it became "the accepted basis and frame of reference for protecting the rights of the disabled" (United Nations, 2003-04b). In 1973, the UN recognized the suggestion that it increase recruitment of disabled people in its own organization, and in 1975, at its 24th session, the Commission for Social Development recommended the elimination of physical and architectural barriers that were preventing "the full social integration of disabled persons." In December of the same year, the UN General Assembly adopted its Declaration on the Rights of Disabled Persons, which stated that "all persons with disabilities are entitled to the rights stipulated, without respect to race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation." The following year, the General Assembly suggested that member states take into account the recommendations highlighted in the Declaration, and designated 1981, the International Year for Disabled Persons (United Nations, 2003-04b).

The period from the late 1970s to the early 1990s proved to be an important transitional time for the disability rights movement, both locally and globally. Local groups such as ADAPT (American Disabled for Accessible Public Transit) raised the stakes by putting their bodies on the line for disability rights-by positioning themselves in front of inaccessible buses (Charlton, 2000; Fleischer & Zames, 2000; Hahn, 2002; Johnson & Shaw, 2001; Shapiro, 1994; Switzer, 2003). Other activist groups, such as the American Coalition of Citizens with Disabilities, led sit-ins at the offices of the Department of Health, Education, and Welfare (HEW) in New York, Washington D.C., Denver, and San Francisco to demand implementation of section 504 of the 1973 Rehabilitation Act. Protestors in San Francisco remained in HEW offices for 25 days in 1977, making it the longest occupation of a federal building by political protestors in U.S. history (Longmore, 2003). At the global level, the UN adopted an increasingly progressive position on disability. Following the First Founding Congress of Disabled Peoples International, held in Singapore in November and December 1981, the UN adopted its World Programme of Action concerning Disabled Persons, shifting disability policy toward three main areas: prevention, rehabilitation, and equalization of opportunities. Then, on December 3 1982, the UN General Assembly declared 1983-1992 the United Nations Decade of Disabled Persons (United Nations, 2003-04c).

The international disability rights movement gained momentum throughout the 1980s. From Brazil to South Africa, Zimbabwe to India, Thailand to Nicaragua, and most places in between, people with disabilities were organizing and demanding that their voices be heard (Charlton, 2000). National governments began to respond. Though there had been early attempts at inclusion, such as Section 504 of the United States' 1973 Rehabilitation Act and other laws designed to mainstream educable children with disabilities, antidiscrimination laws and policies designed to protect the civil rights of people with disabilities were not passed until the 1980s and 1990s. Canada was one of the first countries to protect the legal rights of its disabled citizens with its Charter of Rights and Freedoms (1982). Shortly thereafter, Germany passed its Severely Handicapped Persons Act (1986). South Korea passed its Welfare Law for Persons with Disabilities in 1989. In the nearly twenty years since the United States passed its Americans with Disabilities Act (1990), there have been approximately 85 major disability laws passed in more than 75 countries around the world (Disability Rights Education and Defense Fund, 2008). In most countries, including those in the vanguard of disability rights issues, the end of legal apartheid did not always result in equally vigorous enforcement of those laws, nor did it necessarily produce a concurrent rise the relative standard of living of most disabled people. In some countries, like the United States, there was a marked backlash to legal challenges made by disabled claimants (Johnson, 2003). This, however, should not minimize the tremendous gains that disabled people and their allies achieved at the end of the twentieth century.

At the root of the international disability rights movement is a fundamental rearticulation of what it means to be disabled. Early on, activists abandoned

what they referred to as a medical model of disability and began fashioning a socio-political model of disability. Put simply, the socio-political model of disability makes a critical distinction between impairment and disability and places the voices and experiences of disabled people themselves at the center of any analysis of their lives. It roots disabled people's oppression in social, cultural, and environmental barriers that disable them, not in any individual deficit or impairment (Davis, 2002, 2006b; Oliver, 1990; Shakespeare, 2006; Thomas, 2002; Tremain, 2006a, 2006b). As The Union for the Physically Impaired Against Segregation (UPIAS) explained, disability is "a form of [socially constructed] disadvantage which is imposed on top of one's impairment, that is, the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments" (quoted in Tremain, 2006b p. 187). Early, mostly white, mostly male, mostly spinal cord injured advocates of the sociopolitical model of disability focused almost exclusively on physical impairments. More recent movement participants influenced by feminist, queer, and critical race theory, as well as disability studies, have expanded the socio-political model to include a broad range of impairments, such as mental illness, learning and developmental disabilities, and chronic illness (Barnes, Oliver & Barton, 2002; Davis, 2006a; Longmore & Umansky, 2001: Smith & Hutchison, 2004; Tremain, 2006a, 2006b). The advent of the disability rights movement and the socio-political model of disability have enabled activists, artists, and scholars to reposition the disabled subject and ultimately redefine disability itself. Smith & Hutchison note (2004), "Gone are the days of a simple and dominant physiological or medical definition of disability" (p. 1).

Concomitant with this new understanding of disability has been a burgeoning disability culture movement that seeks to give meaning and voice to the lived experience of disabled people while also critiquing dominant modes of cultural production and the place of the disabled subject in literature, film, poetry, dance, theater, painting, and other cultural forms. Communitybased arts initiatives and independent artists and groups are thriving in the United Kingdom, which historically has been the home of a vibrant, and quite vocal, disability rights movement. Disability art and artists are gaining a foothold in other countries as well. In Canada, for example, organizers at Ryerson University launched their first disability cultural event in 2000, which was followed by other cultural events in Vancouver and Calgary. In 2006, the artistic director of Stage Left Productions, also in Calgary, received funding to start a national Disability Arts and Culture Network (Gorman, 2007). Disability art and artists are critical both to the larger movement and to its broad rearticulation of what it means to be disabled, because they subvert commonly held expectations and assumptions, not only about the capacity of disabled people to produce art, but about disability and aesthetics.

Perhaps the most important product (other than numerous legal changes) of the disability rights and culture movements has been the almost simultaneous rise of disability studies. As an active, integrative, interdisciplinary academic endeavor, disability studies seeks to explore and analyze disability from the perspective of the social sciences, humanities, and arts, not the medical or applied fields. Disability studies programs, initiatives, seminars, and projects in numerous universities around the world have been flourishing since the early 1990s (Taylor & Zubal-Ruggieri, 2008). Organizations such as the U.S.-based Society for Disability Studies, the Canadian Centre on Disability Studies, the Canadian Disabilities Studies Association, the Asia-Pacific Disability Development Centre, the All Russia Society of People with Disabilities, the All Russian organization, New Choices, and the All Ukrainian Association of Disability Organizations are only a few examples of the types of organizations at the forefront of the global disability studies movement.

By discarding the notion that disability is negative and rooted in the individual, and by thinking critically about the taken-for-granted nature of various diagnoses, labels, categories, and conditions, disability studies scholars have been able to develop a powerful understanding of what it means to live differently in the world. While all disability studies scholars use their work to combat the stigma (Goffman, 1963) associated with disability and expand popular notions of what qualifies as the human and the livable (Butler, 2006), there are some scholars who take a more incisive approach to the study of disability. This latter group of scholars uses the socio-political model, along with other theoretical frameworks, such as feminist, queer, critical race, and Marxist theory both to highlight and to analyze the oppression under which most disabled people live, and reveal the central role of class, race, gender, and sexuality in the formation of disabled identities-something recent theorists refer to as intersectionality (Barnes,

Oliver, & Barton, 2002; Charlton, 2000; Davis, 2006a; Longmore & Umansky, 2001: Smith & Hutchison, 2004; Tremain, 2006a, 2006b).

Christine Sleeter's important 1987 article, "Why is there learning disabilities? A critical analysis of the birth of the field in its social context," is an excellent example of this second type of disability studies scholarship. In her analysis of the creation of the category "learning disabled," which occurred in the United States during the early 1960s, Sleeter argues convincingly that the standard historical narrative is not the only available explanation. This category of disability is deeply rooted in dominant notions of progress and consists of a standard story of schools, parents, and medical and psychological experts identifying, researching, and solving a problem that has always existed, and by the early 1980s affected 41% of students enrolled in special education and 4.4% of all students enrolled in public schools. After surveying the available data, Sleeter argues (1987, p. 212) that the category learning disabled did not emerge organically and was not merely discovered by concerned adults, but rather that it was created for a social and political purpose: "to differentiate and protect white middle-class children who were failing school from lower class and minority children." "Rather than being a product of progress," Sleeter continues (1987, p. 212), "the category was essentially conservative in that it helped schools continue to serve best those whom schools have always served best: the white middle and upper-middle class." Sleeter's article is worth revisiting because it clearly shows the forceful critical analysis we can begin to engage in when we wrench ourselves free of the powerful grip of standard narratives of medical and scientific progress and taken-for-granted categories of disability.

Disability studies scholars, and activists and artists, do not seek to deny or to minimize the existence of impairment. Rather, they work to show that dominant ideas about disabled people and various disability categories (like learning disabled) are historically, culturally, socially, politically, and economically contingent; that they change over time and vary by culture, region, and social class. Activists, artists, and academics have shown, moreover, that the social, economic, and psychic costs of disability are increased exponentially in a society that ignores or greatly devalues its disabled citizens. The current move toward universal design in everything from curriculum and instruction to new housing construction is a direct result of the work done by disabled activists, artists, and scholars, as well as their allies, to teach the value of difference and force themselves into the consciousness of the larger society.

Taken together, the disability rights and culture movements and disability studies offer a powerful means of transforming our lived experience by supplanting notions of disability as an individual deficit in need of cure or rehabilitation and by uprooting ideas about disabled people as difficult, passive, childlike, or asexual, as angry, bitter, and combative, or as successful, super-human individuals who have overcome their disability-the myth of the super-crip. Yes, we can change. We as a society can use disability studies, as well as the important gains made by the disability rights movement and the insights of the disability culture movement to change the subjective experience of people with disabilities. But only if we, like President Obama, work at the grassroots level-both locally and globally-to build coalitions among a broad range of actors, especially educators, administrators, service providers, and students who can incorporate disability studies concepts not only into their work, but into their lives outside the classroom and the office. These coalitions, moreover, must extend beyond individual impairments, and perhaps more importantly, beyond class, race, sexuality, gender, national, and religious divides.

# Changing Laws, Changing Minds, Changing Ourselves?

Building coalitions and mobilizing an historically marginalized and alienated citizenry is not easy. In this next section, I will offer a comment that I hope addresses the complexities of not only building and sustaining a broad-based social movement, but also engaging in disability studies scholarship and incorporating the social model of disability into everyday practice. I will conclude by providing at least one possible course for the future.

As noted earlier, various groups have a long history of disability activism and community building. Yet, scholars (and activists) agree that for the last forty years, a diverse lot of people with a broad range of disabilities who loosely identify with the modern disability rights movement and espouse the socio-political model of disability have been transforming their own lives and the world around them. They have forced society to grant disabled people access in the very broadest sense of the word; access to education and employment; to healthcare and various disability benefits; to print media, the internet, and telephone communication; to buses, trains, and airplanes; and to local parks, movie theaters, taverns, and restaurants. The level of access movement participants have obtained remains woefully incomplete, and many of us, like Lennard Davis (2002), long for the day when we can "extend the concept [of disability] so that it applies broadly across society as a civil right for all-the right to be ill, to be infirm, to be impaired without suffering discrimination or oppression" (p. 1). Yet, it is undeniable that we (disabled people) have made tremendous gains over the last forty years. We are now rolling, limping, signing, tapping, shouting, jerking, and sometimes sulking our way through the lives of "ordinary" citizens. Our mere presence speaks volumes for the decades-long struggles of people with disabilities, their allies, friends, family members, and advocates to dismantle many of the legal and structural barriers that had historically kept us segregated and isolated, lonely and desperate.

Part of the success of the disability rights movement and of disability studies has been rooted in its ability to expand the definition of disability to include a broad range of impairments, illnesses, and conditions, and to show that disability will touch everyone at some point in their life. Whether we become disabled or not, all of us at some point in our lives, will feel the effects of disability, as we age, as we interact with co-workers, clients, and customers, and as we care for the ones we love. The tremendous diversity among the world's disabled population and the broad range of experiences we all have with disability have been a source of empowerment. They have also been a point of contention. On one hand, a very broad definition of disability enables movement participants in the United States, for example, to claim that they are part of the largest minority group in the country. At about 54 million, people with disabilities make up about 20% of the U.S. population (Siebers, 2008). These numbers and percentages have been critical in making civil rights claims against the state. On the other hand, this broad definition of disability makes it difficult to think about and talk about a shared identity, a common culture, or a collective consciousness. The fact that only about 15% of disabled people are born with their disabilities-85% of disability is acquired-and that about 80% of the 500 million people with disabilities live in what is commonly referred to as the "developing" or "third" world only serves to complicate both the movement and disability

studies (Charlton, 2000; Siebers, 2008).

For years, scholars have been theorizing about the alienation that many disabled people feel. Most authors argue that it is one of the powerful legacies of the individualization, medicalization, and pathologization of disability (Siebers, 2008). We (disabled people) are divided, the argument goes, by our impairment; by medical professionals, physiotherapists, social workers, educators, and a larger society that sees us as nothing more than our own individual impairment(s) and treats each one of us as an individual case, patient or client, different from all the other cases, patients or clients. *They*, of course, can find similarities in our physiology, our neuro-chemistry, our symptoms, but we remain isolated and alone, trapped by our own internalization of a depoliticized, pathologized, individualized, and ultimately devalued sense of ourselves. Only when we shed this false consciousness can we become free to see the world and our place in it for what it really is, only then can we see the discrimination, segregation, isolation, and outright violence and oppression we all face every day.

According to this liberal ideology, we (the disabled) become empowered when we embrace our disabled identity and make it our own; when we begin to associate, demonstrate, and generally identify with other folks who have done likewise. Once we have experienced this consciousness raising, we are (in most situations) able to live life on our own terms. Some of us choose to "let our freak flags fly." We flaunt our (disabled) bodies and revel in our (usually hetero-) sexuality. Others among us choose to "pass;" to minimize the extent of our impairment or mute our disabled identities (usually when in the presence of mixed company). Most of us, however, choose to live what Siebers (2008) calls a complex embodiment, which is some mix of all of these extremes. Within this liberal framework, everything we choose to do, every utterance we make, and every cultural artifact we produce gets politicized. The personal becomes political (Siebers, 2008).

While this is a very powerful and important analysis of the alienating effects of disability, I would briefly like to consider an alternative explanation. I would like to argue that it is not necessarily a false consciousness that keeps us isolated and alone, living on the margins of society, but rather a lack of access to much needed support and economic resources. Much of the world's disabled population lives in abject poverty. The rise over the last thirty years of a global neo-liberal economic order that

favors privatization, so-called free market economics, and military engagement has only served to deepen the plight of people with disabilities, especially those living on the periphery (Charlton, 2000; Holden & Beresford, 2002; Rioux, 2002). People who have no prosthesis cannot choose to pass. People who have no wheelchair cannot choose when or if they will use one. People who have no access to a screen reader or a Braille printer may be forced to live in ignorance. People who never learn to sign may never feel part of the larger deaf culture. And people who have no access to education, or are forced out of poverty to work from a very young age, may never have the opportunity to come out and identify as disabled. For a long time now, we (activists, artists, and scholars) have been talking about how disability is socially constructed (Liachowitz, 1988). It is time we reconsider how disability is socially created-through war, famine, inadequate healthcare, fierce competition for scarce resources, as well as rising profit margins, and general neglect.

It is also time that we begin to think seriously about our own privileged position. Now more than ever, we as movement participants, artists, and academics, or as service providers, educators and administrators need to take a step back and think about all of the benefits that our class, race, gender, (dis)ability, sexuality or citizenship status bring us. Yes, we can change. But the change must begin with us. We need to begin to think more critically about the human relations that create disability and perpetuate stigma, and we need to be more reflexive in our scholarship, our teaching, and our service provision. Ultimately, this change must extend beyond our own minds, our own 'best practices', and our own experiences to address the larger systemic causes of disability and the social and economic inequality that separate us. This is what disability studies and the disability rights and culture movements seek to do.

### Conclusion

When thinking about the future of disability and President Obama's call for change, it might be beneficial to contemplate ever so briefly the origins of his campaign slogan. A strikingly similar variation of "Yes we can change" was first uttered by the U.S. (Yuma, Arizona) born, mid-twentieth century labor organizer and civil rights leader, Cesar Chavez. In the midst of organizing migrant farm workers in California and other states throughout the southwestern United States, Chavez began declaring, "Si se peude," often translated into English as, "Yes, we can!" (Ferriss & Sandoval, 1998; Levy, Moulton, Ross & Levy, 2007). If we have learned anything from the social turmoil and civil rights struggles of the post-World War II period, it is that although it can be difficult and even deadly, ending legal apartheid is much easier than empowering those individuals, like migrant farm workers, who historically have clung precariously to life on the margins of society.

Though they have always led a tenuous existence, people with disabilities have been especially oppressed at least since the beginning of the nineteenth century, when industrialization and a growing market economy, as well as new theories of human evolution and statistical normality, or the bell curve, made it increasingly difficult for them to make their way in the world (Davis, 2006c; Finkelstein, 1980; Gleeson, 1997, 1999; Oliver, 1990). In some ways, little has changed. Legal apartheid has ended (in most countries), but rigid social, cultural, and economic barriers remain stalwart. As Harlan Hahn has noted (2002 p. 183), "Animus toward disabled people seems to be an endemic and deep-seated characteristic of most cultures of the world." In order to move forward and break down the barriers that still separate many of us from society, we (disabled people) must, along with our allies, work toward not only empowering ourselves, but also empowering those around us so that together we can affect real lasting change. Teaching, learning, and working from the disability studies perspective and incorporating the socio-political model of disability into our thinking and our practice will go a long way in empowering us all.

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# About the Author

Dr. Rembis is a visiting scholar in the Department of American Studies and the Department of History at the University of Notre Dame. In Spring, 2010, he will also be the inaugural fellow in the Center for Disability Studies and the Department of History at the University at Buffalo. He has published widely on disability and eugenics. His work, which has appeared in Disability and Society; Disability Studies Quarterly; Sexuality and Disability; and History of Psychology, has won several awards, including the 2008 Irving K. Zola award, awarded annually by the Society for Disability Studies to emerging scholars. His first book, 'Defining Deviance: Sex, Science, and Delinquent Girls, 1890-1960' is forthcoming from the University of Illinois press.

# **Professional Perspective**

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In his article, Michael Rembis, Ph.D. offers a history of disability activism, rights, culture, and studies. More than this, Dr. Rembis has elicited a call to action for service professionals. Those of us in the disability community—professionals, scholars—question the gap between disability studies and our practice. While we would all swear by the social model of disability, is there congruency between our values and our action?

What I find most heartening about this article is the reminder that disability activism is alive and well. While we are often criticized for our lack of collective action. our inability to find a common voice, a shared experience, Dr. Rembis reminds us that we have a rich history punctuated with major accomplishments in procuring legislative recourse, changing the face of design, and increasing access. He does point out the challenges we in the disability community have in identifying with one another, also, the societal resistance with which we are met when asking to be considered a cultural group. These persistent and interconnected barriers will impede our action. Therefore, we must take pause and ask why. In an effort to propel this movement, how can professionals grapple with these concepts, engage students, and challenge colleagues to advance our communities?

As professionals, we must consider our own conceptualizations of disability. Do we consider ourselves benevolent gatekeepers to accommodations, "problematizing" our students and diagnosing their individual needs? Or do we consider ourselves agents of systemic change? How do we intersect with the disability community, or validate disability identity? Can we connect to the disability history Dr. Rembis presents in this article? What are we representing to disabled students and the community at large through our professional actions?

Perhaps the role of service provider should not be limited to determining individual accommodations and facilitating campus access, but expanded to that of an ambassador for disability culture. We have the unique opportunity to reframe disability, push forward progressive ways of thinking, and challenge antiquated ideas. In our roles, we represent disability to our campuses and community. This is a big responsibility—one that, if we do not take it to heart, will simply maintain status quo for the disability community. However, should we heed this professional call to action, we can reshape disability one changed mind at a time. So, can we be more critical of ourselves, our practice, our profession? Can we demand more congruency between our values and our practice? Can we pioneer new ways? Yes we can.

# Using Disability Studies Theory to Change Disability Services: A Case Study in Student Activism

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## Abstract

In 2001, a group of student activists at Syracuse University started an organization called the Beyond Compliance Coordinating Committee (BCCC). The BCCC activists used disability studies theory to engage the campus in conversations about disability and inform significant change in the way Syracuse administration think about disability. This paper explores what makes Syracuse unique and what happened between 2001 and the present day. It concludes with recommendations for disability services providers on how they can use the experience at Syracuse to inform their thinking about campus culture and services.

## Introduction: Why is Syracuse Unique?

Disability Studies at Syracuse University is indebted in part to the last two centuries of the history of activism that has occurred in the Syracuse area. The history of Syracuse reveals a community that was ripe for progressive social action. In the 1850s, Frederick Douglass frequently visited Syracuse from his home in Rochester, New York, often to give public orations against slavery in Fayette Park. The city operated multiple stops along the underground railroad via the Reverend Jermain Loguen; residents protested the Fugitive Slave Acts by, for example, helping Harriet Powell and "Jerry" Henry escape capture. In 1851 and 1861, Susan B. Anthony traveled to Syracuse to attend the city's Anti-Slavery Conventions.

During this time, in 1854, Hervey Wilbur, following the educational philosophy of Edouard Seguin, opened the New York State Asylum for Idiots in Syracuse. In declaring that "idiots" can be taught, Wilbur set up one of the first schools in the United States for people with intellectual disabilities. In 1855, 89 students attended; by 1912, 500 children lived at the school and in the allied farm colony (Taylor, 1999). By 1998, the last five residents moved out of what was, by then, known as the Syracuse Developmental Center. Though certainly outdated and even "wrong" in their methods, the educational philosophies of Wilbur and Seguin represent a local lineage that eventually progressed to the development of socio-political understandings of disability.

In 1870, sixteen years after Wilbur opened his school, the Methodist Episcopal Church passed a resolution to charter Syracuse University. The University offered courses in algebra, geometry, Latin, Greek, history, physiology, elocution, and rhetoric. The College of Medicine was founded in 1872. After this period, many disability activists and scholars emerged from the Syracuse area. Elizabeth Farrell, the founder of the Council for Exceptional Children and an early, progressive educator, lived close to Syracuse in 1877. She adhered to, but then eventually veered from, Seguin's teachings. In the twentieth century, other important disability rights activists emerged: self-advocates like Michael Kennedy, Pat Felt, and Al Zappala, and scholars such as Wolf Wolfensberger, Gunnar Dybwad, Bob Bogdan, Steven J. Taylor, Doug Biklen, and Burton Blatt.

Today, what makes Syracuse University remarkable are the continued, far-reaching connections among the University and Syracuse communities. The Center on Human Policy, and the expansion of this Center, the Center on Human Policy, Law, and Disability Studies (hereafter "the Center"), is University-based yet highly engaged in the community, including housing the Early Childhood Direction Center, the Disability Rights Clinic, and directing Project Accessible, which works with community stakeholders to increase awareness of issues of accessibility of buildings and services in the area and to create more accessible buildings and services in the Syracuse communities. This article describes how, through student activism, the Office of Disability Services at Syracuse University came to contribute to unique engagement with disability studies theory on campus.

#### From Theory to Activism

Disability Studies at Syracuse University provides foundational knowledge for promoting positive social change on campus and beyond. "Disability studies applies social, cultural, historical, and philosophical perspectives to the study of disability in society" (Disability Studies at Syracuse University, n.d., para. 1). Disability studies diverges from the medical model of disability, which posits disability as something to be fixed and that essentializes the person to the sum of the impairment (Charlton, 1998; Davis, 1997; Gartner & Lipsky, 1999; Linton, 1998; Longmore, 2003; Slee, 1996). Disability studies theory is a synthesis of social constructionism and critical theory that places disability in the political realm, resisting notions of stigma and asserting alliance with other groups excluded because of race, gender, class, or sexuality. Disability studies examines barriers-physical, social, political, cultural, economic-that exist for individuals with impairments. Disability studies theory interrogates the positions that people with disabilities occupy, and have historically been forced to occupy, in political, social, legal, and economic relationships (Thomson, 2000).

While disability studies as a disciplinary field contests inequities, disability services offices focus on providing accommodations and taking up issues of participation. Staff often concentrate on legal and compliance issues, without recognizing a philosophical stance on inclusion and disability. Offices of disability services and disability studies programs are often distant and unconnected. However, disability studies *theory* operates as an academic and abstract critique of power and powerlessness and is transferrable to the practice of disability services. This theory critiques authority, for example, privileging a student's knowledge of him or her self, rather than assuming that a professor or administrator knows best. Disability studies in praxis works to define disciplinary boundaries; yet, disability theory transgresses boundaries and can be applied to multiple locations on campus far outside the disability studies program. Disability studies puts heavy emphasis on the merging of theory and practice and begets activism, as our case study will demonstrate.

Theory and practice converge in the Disability Studies program at Syracuse University, as it encourages students to live what they learn in class. Since the program is grounded in the philosophy of full participation of people with disabilities, it was not likely that when students felt the University was a barrier to the full participation of all students in the program, they were going to stay quiet about it. The faculty of the Disability Studies program all were disability/human rights activists in their own ways. They based their teaching in the notion that disability studies, as a discipline, necessitates action. It is not enough to simply state that people with disabilities should have the same rights accorded all others; these faculty led by example in teaching students that disability studies scholars need to take a stand for the humanity of individuals with disabilities.

The Center on Human Policy, the institutional structure in support of the Disability Studies program, includes staff, associates, educators, human services professionals, people with disabilities, graduate students, and family members of children and youth with disabilities.

The Center has an Advocacy Board composed of people with disabilities, parents, and interested citizens who serve as a collective independent voice on the rights of people with disabilities in the community. The Center is involved with a broad range of local, statewide, national, and international activities, including policy studies, research, referral, advocacy, training and consultation, and information dissemination. The Center is also directly involved in the Disability Studies program, which includes Master's and doctoral programs with concentrations in Disability Studies, a graduate Certificate of Advanced Studies (CAS) in Disability Studies, and a joint degree program in law and Disability Studies, which includes a law degree (J.D.) and a Master's and CAS in Disability Studies.

## Formation of the Beyond Compliance Coordinating Committee

In the Fall of 2001, there was a critical mass of students enrolled in the Disability Studies program. Three new Ph.D. students commenced their degree programs with Disability Studies as their primary academic area. Each self-identified as an individual with a disability and each had an interest in disability that went beyond the Center's historic focus on deinstitutionalization and independent living for individuals labeled with cognitive disabilities. Additionally, there were two, more senior, doctoral students who had research assistantships in the Center on Human Policy and were part of the earliest discussions on disability rights in academia, specifically, at Syracuse University. These five students formed the Beyond Compliance Coordinating Committee (BCCC).

There was a conflux of events that helped BCCC get started and take hold. The Center held regular Wednesday morning staff meetings. During one of these meetings, some of the students expressed frustration with the difficulties they were having obtaining appropriate accommodations. One student, who is blind, never had his books converted to e-text in time for him to read them for class. Another student, who is deaf, had difficulty in obtaining Computer Assisted Realtime Translation (CART) in some of his classes and Signed English interpreters in other classes. In both situations, the staff of the Office of Disability Services (ODS) argued that the accommodations provided were compliant with the laws, even if they did not meet the students' preferences. Also, during this time, the doctoral students at the Center were working on an information packet that eventually became Beyond Compliance: An Information Packet on the Inclusion of People with Disabilities in Postsecondary Education (Cory, Taylor, Walker, & White, 2003). So, issues of accommodations, full and meaningful participation, and postsecondary education were in the forefront at Center meetings. In a meeting in Fall 2001, the idea to form an activist group clicked into place. The need to take action, not simply talk about the issues, became necessary, and the students arranged a meeting to start discussions on what actions they could take to move the University beyond a simple compliance to the law mindset. The students choose the name "Beyond Compliance" because they felt that as long as the University was meeting just the minimal compliance standards of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (504), there was no possibility of equality of opportunity and meaningful participation in the academic community of the university. The students wanted to move University administrators beyond this compliance ethos. Additionally, they chose the phrase "Coordinating Committee" as part of the name for its association with the Student Nonviolent Coordinating Committee, a seminal organization of the Civil Rights Movement that organized sit-ins, freedom rides, and voter registration drives throughout the South during the 1960s.

During the BCCC's first semester in existence, the students wrote a platform. The four strands of the platform reflected aspects of the University that they felt needed to change:

- 1. Reshaping Syracuse University's conception of disability to promote an understanding of disability as a form of diversity.
- 2. University recognition and funding of the Disability Studies program.
- 3. Creating model accommodations exemplifying the University's commitment to equality of opportunity for students with disabilities.
- 4. Hiring faculty and staff members with disabilities within departments across the University.

An early action of the BCCC was recruiting other doctoral students with a passion for disability studies. More students, both graduate and undergraduate, continued to join the core BCCC membership. With the assistance of the Director of the Center on Human Policy, the Committee identified a core group of faculty allies and brought them together for brainstorming and information sharing. At a luncheon meeting, these faculty reviewed the BCCC platform, gave feedback, and suggested next steps for the students. Along with the platform, the BCCC students wrote a more developed position statement, annotating the points of the platform.

In the Fall of 2001, at the request of the students, and with some behind-the-scenes support from the faculty, the Dean of the School of Education met with the BCCC and, after hearing their platform, invited the students to present the platform to the faculty at the next School of Education faculty meeting. This was a moving experience for the faculty and an empowering one for the students. One of the student presenters indicated that it was the first time that she, as a woman with a disability, felt like people were listening to and validating her experiences. The faculty voted unanimously to endorse the platform. And so the work of the BCCC commenced.

## The BCCC in Action

In the Spring semester of 2002, many members of the BCCC were enrolled in a Disability Studies seminar. In this seminar, the class read a book each week and students provided discussion guides and facilitated discussion of the books and issues associated with the books. During this semester, the entire class experienced the frustration of one of its colleague's not being able to fully and meaningfully participate in class. One student, who was a member of this class and also blind, needed his books scanned so that he could access them through JAWS, an assistive technology screen reading program. Even though the books were available to be scanned by mid-December; the books were never scanned in time for him to read them or prepare to facilitate or participate in class discussions. This issue was ongoing, and was in fact one of the events that led to the formation of the BCCC. Therefore, the class temporarily suspended the readings and focused on strategizing a protest of the ODS for this pattern of denial of access of course materials for a student.

During, and outside of, class, students wrote a letter to the Director of ODS pointing out that although books for the class were provided to ODS substantially prior to class meetings, this material had not been made available to the student with adequate time to prepare for class, if at all. The fact that he was unable to meet the requirements of the course, due to lack of provision of the books, was, in the class's view, discriminatory and compromised the academic process. In this letter, the class stated that its expectation was that for the remainder of his studies at Syracuse University, the student would have his course materials in electronic format one week prior to each class so that he could adequately prepare and participate in a productive and effective way, enabling his colleagues to benefit from his contributions.

All eight members of this seminar signed the letter of protest, and on February 15, 2002, a small group of students hand delivered the original to the Director of ODS and copies of this letter to the Chancellor, Vice Chancellor, Vice President of Undergraduate Studies (who also served as the 504 Compliance Officer for the University), the Associate Vice President of Undergraduate Studies, the Director of Student Service and Retention, and the Dean of the School of Education.

While the class was hopeful that these letters would yield fruit in the student's receiving his books in electronic format in a timely manner, he did not receive the next week's readings. The Director of ODS phoned the student, told him that the book was not ready, and that she would be willing to read the book to him. Of course, he refused. A human reader does not provide the independence and speed that the student had through the JAWS program. On February 18, the class received a memorandum of reply from the Vice President of Undergraduate Studies / 504 Compliance Officer, in which he refused to investigate the allegations of discrimination and demanded that the class provide evidence of our accusations.

On February 20, the class received an e-mail from the Dean of the School of Education who gave her assurances that administration was working cooperatively to reach understandings and to create solutions to the immediate issue of access to class material. The Dean asked that the class share its response and supporting materials with her before responding to the Vice President / 504 Compliance Officer. The students briefly met with her, and then the class responded on February 22, 2002, in a letter to the Vice President / 504 Compliance Officer, delivering copies to the same individuals who received the original protest letter. Included in this letter that students provided on November 30, 2000, was the ODS policy and a chronology of events documenting how this policy was violated, samples of improperly scanned materials that were difficult to read through the JAWS software, and five e-mail communications between the student and ODS, in which, among other things, ODS admitted their tardiness in preparing his materials.

One of the outcomes of this protest action was that these students were invited to meet with the Vice Chancellor of Syracuse University. In late February of 2002, representatives from the BCCC met with and presented the BCCC Platform to the Vice Chancellor, Vice President of Undergraduate Studies, and the Graduate Studies Dean of Syracuse University. Similarly to the presentation to the School of Education faculty, students made a conscious decision, in a BCCC strategy meeting before the meeting with the Vice Chancellor, to focus on the Platform, not with specific complaints against ODS. The group wanted to make reasonable suggestions such as, for example, establishing a task force related to accessibility issues on campus. While one of the faculty allies attended this meeting, the faculty who could not attend expressed unanimous support for the BCCC and its Platform. The breadth of support was wide. In presenting the Platform, the group related it to the academic mission of Syracuse University, that by integrating a disability studies perspective into research, teaching, and community service at Syracuse, disability would become recognized as a form of diversity. One student addressed the fourth strand of the Platform, hiring faculty and staff members with disabilities within departments across the University, in the context of suggesting the joint appointment of a scholar with a disability to Disability Studies and another discipline. While the group did not address the immediate ODS issue specifically, the issue was alluded to by suggesting the possibility of creating the summer position for a graduate assistant to help review university accommodations policy and to participate in Teacher Assistant orientation to ensure that issues around accommodations were addressed during orientation.

### **Administrative Outcomes**

The group's actions did have one, almost immediate, impact: On March 1, 2002, the Vice President / 504 Compliance Officer sent a memo to three BCCC members in which he introduced his proposal for a Summer 2002 and Academic year 2002-2003 "pilot" plan "to secure the timely production of alternatively formatted materials for disabled students." He stated that he intended to present this plan for the Chancellor's approval and that he intended to share it with the student, "his professors, and those of his peers who have written on his behalf." By mid-April 2002, the pilot plan had not been shared, and the group was unaware if it had been developed at all. On April 19, 2002, students again hand delivered another round of letters, addressed to the Vice Chancellor, thanking her for meeting with the representatives of the BCCC in February, but expressing continued concern for the arbitrary way that ODS creates policy that impacts students with disabilities, and asking her to develop a formal means for students and faculty to be active participants in the crafting of disability policy. To this letter was attached a chronology of events to remind the Vice Chancellor of the history of the issue and reiterated the need for a formal mechanism to be in place for soliciting and incorporating student input into the accommodation process.

The frustration the students expressed with the accommodations was not frustration with a specific

person. The BCCC platform focused in part on the need for state-of-the-art accommodations, both low tech and high tech, that would allow students to achieve in their classes. Students saw Syracuse as having the opportunity to design and implement model accommodations. There was a possibility for Syracuse to become a national leader in the way campuses thought about and implemented accommodations, which would further articulate the University's national leadership in Inclusive Education and Disability Studies. On a campus that had a reputation for teaching, and acting on, inclusion, there was even more of a need, the students felt, for the campus to live inclusion.

Shortly after the BCCC's meeting with the Vice-Chancellor, the Office of Disability Services experienced a change in staff. The director who was in place in 2001 and 2002 was put on administrative leave, and eventually, an Interim Director was hired. This new Director had a long career in disability services and he was recruited as someone who had deep knowledge of disability and who would develop rapport with the students. He understood, and for the most part, agreed with the BCCC platform and did an excellent job of balancing the demands of meeting the University's legal obligations and administrative hurdles while listening to the students and incorporating their work into the design and implementation of the work of his office. He would often state that ODS and the BCCC were working towards a common goal and that sometimes their methods and ideas would align closely, and other times they would be further apart, but they were never oppositional. After a year as the Interim Director, he applied for and earned the permanent Director position.

## Working Group on Disability

In Fall 2002, in response to the students' request for a clear mechanism for participation in disability policy and procedure, a Working Group on Disability was formed, in which members of the BCCC, the Associate Vice President for Undergraduate Studies, the Director of the Office of Disability Services, and the Office of Design and Construction would collaborate on resolving accessibility issues at the University. At the present time, almost eight years later, the Working Group is still active, and its members include BCCC representatives, Graduate Students, The Director of the Office of Disability Services, the Assistant Director of Design and Construction, the Associate Director of Career Services, Librarians, and Faculty members. In the past, the Working Group has also collaborated directly with the Division of Student Support and Retention. The Working Group's main goals are to examine, address, and resolve urgent issues concerning students with disabilities on campus, and to establish communication between students with disabilities, staff, faculty, and University administrators. The Working Group functions mostly as a conduit in that concerns come to it via the BCCC, the Office of Disability Services, and other means. Once a concern is logged, the group works collaboratively across departments and services in order to remedy the situation.

In the early days, the working group struggled to find a common way to both function and to formulate goals. Within a semester, the Associate Vice President for Undergraduate Studies was able to realize that to really "work" on issues, all the relevant players needed to be brought to the table. Each time an issue came up, he invited the stakeholders to a meeting, and the details of a solution were brainstormed and implemented. Early issues the Working Group tackled included the review of the new ODS policy manual, creation of a snow-removal procedure (this was, after all, Syracuse, New York), and issues around the consistently broken elevators in the Law School parking lot. Later, the Working Group continued to look at barriers to accessibility, both large and small, while always asserting that compliance was a starting point, not an ending point.

Once the BCCC was established on campus as an advocacy group, members started to receive complaints surrounding the lack of physical accessibility of the corporate-owned campus bookstore, among other barriers to access. The bookstore kept all of their textbooks in the basement, accessible only by a steep flight of stairs. The obvious solution, of moving textbooks to the first floor, was not as simple as it would seem, there were still three steps on the main level that would disallow full access. Once the issue was prioritized in 2007, the Working Group formed a coalition that included Design and Construction (the bookstore leased the space from the University), the managers of the mall in which the store was located, and BCCC representatives. Essentially, a majority of stakeholders were invited to problem-solve collaboratively. A few interested parties offered to open a rear, ground floor, entrance which would remain open for those who needed to use it. However, the BCCC and the Working Group sought to go "beyond compliance" and would not settle for a back or alternate entrance.

Because the textbooks were kept in the basement, the arguments of the BCCC centered around the idea that the bookstore, as well as their customers, would all benefit from easier access to the textbooks. In this sense, the advocacy of the BCCC focused on a resolution to the problem of inaccessibility in the context of universal design. After multiple discussions, the corporation that owned the bookstore decided not only to move the textbooks upstairs to the first floor, but also to install a beautiful, red-oak hardwood ramp that led to the textbook section. The bookstore received public acknowledgement in the school newspaper, as well as increased business. Moreover, the BCCC improved its relationship with the Mall in which the bookstore was located—and this led to the next action.

Because of the BCCC's improved relationship with the managers of the mall, members became involved in the planning, design, and construction of the Fitness Center that would be located in the mall. The groups worked collaboratively to design large and accessible unisex bathrooms, bright and contrasting colors for the floor, universally designed fitness equipment, non-fluorescent lighting, and individual control of the television noise.

Challenges of the Working Group mainly consist of the Group's attempts to balance long-term solutions and short-terms needs. Although the Group would like to make every space on campus physically accessible, there are still some physically inaccessible buildings and spaces on campus that remain so because of the University's long-term plans for construction and renovation. Other issues still to address include: parking assignments which are currently given out based on seniority not need, a strip of old buildings that offer student services (Legal Services, LGBT Resource Center) that remains inaccessible, the University website's accessibility and usability, and continuing snow removal issues. But overall, the Working Group has coalesced into a formidable force on campus that collaborates across identities and roles in order to address pressing issues, that while they may appear to be singularly disability-related, are in fact a benefit to the entire University community.

#### The Chancellor's Task Force

In May 2005, shortly after taking her post as Chancellor of Syracuse University, in light of the campus climate and her personal and professional commitment to inclusion, the new Chancellor established the Task Force on Disability. Led by two faculty and the Director of ODS, the goals of this Task Force include consideration of centralized funding, the development of future programs, and the potential of Syracuse University to again be a pioneer in innovative leadership, model accommodations, and the integration of disability studies in the University's academic mission. In September 2007, the Report of the Task Force was completed, establishing Syracuse University as a leader in moving beyond compliance with the law for accommodations and in collaboration on disability issues. Generally, the recommendations were to strengthen disability policy, programming, technology, and services across the University community. Challenges included: physical access, communication access, technology and virtual access, academic and program access, staff and faculty with disabilities, students with disabilities, and University life. Other prominent features of the Report include the push to publicize the core value of disability as a form of diversity, the need for regular staff and faculty training, the development of comprehensive plans by departments, schools, and services for disability inclusion, the adoption of a policy against harassment, and the need for a disability link on the University's homepage. The Task Force will to continue to operate within the values set forth by the Chancellor-a steadfast commitment to social justice and equality.

#### **Campus-Wide Educational Programming**

The Beyond Compliance Coordinating Committee, in support of the mission of systemic change, provides campus-wide educational programming that supports a positive climate for disability. Since 2002, the BCCC has provided speakers, presentations, and performances, always without admission fees, that include scholars and speakers such as Eli Clare, Keith Wann, Dan Keplinger, David Roche, Jonathan Mooney, Greg Walloch, Lennard Davis, Rosemarie Garland-Thompson, and Chris Bell. In 2003, the BCCC began its annual film festival with "Reflections on Diversity: Disability in Film." During this film festival, the BCCC brought in guest speakers to introduce the films and engage in question, answers, and discussion after the films. The BCCC worked with different departments in the School of Education and across the University to obtain funding for honoraria and film rights. The films were shown over a semester, and were well attended each week. The 2004 festival was called "Laughing with Us: Comedy and Disability;" this

three day festival featured films, television episodes, and stand-up comedy that satirized and parodied stereotypes of disability. The festival continued annually through 2007. Then, in 2008, the BCCC hosted the first bi-annual Disability Studies Graduate Student Conference, with Brenda Brueggemann, professor of Women's Studies and Deaf Studies Scholar, as the keynote. Additionally, since 2005, the BCCC has organized Brown Bag lectures in which graduate students and/or faculty share their work in a community and cross-disciplinary space. The Beyond Compliance Award ceremony, started in 2004, is an event in which the BCCC celebrates a department, faculty, staff, student, or student group who deserves public recognition of their work on disability issues.

The BCCC has also presented to University Deans on universal design in learning and has made presentations to classes and national and international conferences. Because the BCCC has allied itself with administration, organizations, and services across campus, the group is able to respond quickly to conflicts or issues that occur day to day. For example, in 2004, the BCCC published a position statement that problematized an educational campus program called the "Tunnel of Oppression." The program, part of an effort to promote diversity by the Office of Residence Life, creates a haunted house-like production that simulates situations of oppression and discrimination. In one instance, the program depicts someone in a wheelchair trying to painfully squeeze into a door that is too narrow. In the position statement opposing the program, the BCCC points to the fact that the event becomes a "freak show" and that simulation and role-playing oversimplifies the complexity of oppression. The simulations all too often leave viewers with a feeling of distaste for those with whom the production is trying to "help." Though this is not the first nor the last position paper published by the BCCC, it helped the group gain significant public presence in efforts to understand disability as a complex, cultural identity whose oppression is not quickly remedied through simulation.

#### **Conclusion: What We Can Learn**

Disability studies is intimately tied to action. In this sense scholars and activists working in the field connect their work to communities outside academia. While the University is often perceived as the center of the City of Syracuse, in fact, the University is "surrounded by" the many communities that make up the city of Syracuse. This sense of interconnectedness between and among the University and the "surrounding" geographies is not forgotten when disability studies is put into action.

This case study is an example of the power students have to inform change on campus. While Syracuse University enrolled 19,084 graduate and undergraduate students in 2007 (22% African American, Asian American, Native American, and Latino students), any college campus, regardless of demographics or size, can produce outcomes similar to what this study describes. There have been many active undergraduate and graduate student groups on campuses across the United States. The State University of New York (SUNY) at Geneseo, for example, has an undergraduate group called Students Educating About Ableism. An inaccessible campus led the group, in 2008, to lead a tour around campus demonstrating the barriers that existed. They have also heavily critiqued and taken action to develop a system to transport students with disabilities on campus, a system that is already in place at most of the SUNY campuses. A student group at Ohio State University called Unity works on ongoing projects that include social, educational, and cultural events. They celebrate out loud Disability Awareness Month on campus, bring speakers, provide entertainment, organize adapted sports, and art exhibitions. Also, a chapter of the Autism Self Advocacy Network has recently been established on The Ohio State University campus. And, of course, University of California, Berkeley, which is known for early disability rights actions in the 1960's, has a 40+ year-old Disabled Students' Union. Clearly, there is a connection between a campus having a disability studies program and it's also having an active disabled student group. However, advocacy groups can still be established at schools that do not have a disability studies department.

This case study provides lessons in applying disability studies theory across any campus, with or without a disability studies program. Disability services staff can create and administer services and accommodations while working with student advocates. The BCCC helped University administrators and faculty re-frame the "problem" of disability on campus. The students worked with the University to assist them in seeing compliance with the ADA as a starting point for conversations, not an ending point. Therefore the University could move "beyond compliance" to a place where students with disabilities are valued for their input and diversity. The student members of the BCCC worked with the University to, whenever possible, change the environment, rather than expect change from students who use the Office of Disability Services. Disability studies theory insists that the "problem" with disability is not in the person, but in the environment. The problem is not a student's inability to walk unassisted, but the flight of stairs they are being expected to ascend. A task force, or working group, consisting of advocates and administrators can benefit any campus.

The work of addressing systemic change in ways of thinking about disability was accomplished through programs and outreach, as well as through conversations and protests over campus activities the BCCC felt were discriminatory or oppressive. The annual film series helped raise awareness of disability and were accompanied by discussions that framed the films in the context of the social construction of disability. Additionally, events such as the e-books protest and policy letter against the Tunnel of Oppression, and the meetings with administrators that followed these protests, allowed students to share their philosophy with a wider audience. Although disability service providers may not want to participate in protests on their campuses, they can provide outreach programs and engage in thoughtful conversations with faculty and staff about the representations of disability in campus programs.

This case study also illustrates the power of having students who are served through offices of disability services involved in the process of creating the services. The Working Group that was formed in collaboration with University administration solicited direct input from the students on issues of accessibility on campus while allowing those students to be part of the solution process. It empowers the students and provides administration real expertise to solve problems.

Disability service providers can also learn from this case study how to work with and support student advocates. The Director of ODS maintained throughout all discussions that his office and the BCCC were working toward a common purpose. Although their strategies, mechanisms, and decisions may vary, the larger objective was the same. This strengthened the directors' relationship with the BCCC and kept it from getting adversarial, allowing him to maintain a positive working climate with the students. Disability service providers should identify as allies to students with disabilities, allowing them to support the goals of student advocacy groups. Additionally, through this case study, disability services staff can learn that student access to the staff and transparency of operations can support a positive advocacy spirit.

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# **Professional Perspective**

#### Carol Funckes Associate Director, Disability Resources University of Arizona

In their article, Cory, White, and Stuckey describe the impact that student activism has had in supporting the development of a positive climate for disability at Syracuse University. The impetus for change was students' experience that the compliant delivery of accommodations often does not support "equality of opportunity and meaningful participation." Informed, connected, and emboldened by disability studies, the students' response was community organization and activism rather than the more common individual complaint.

This case study provides a compelling example of how exposure to the historic, political, economic, and cultural experiences of disability taught through disability studies can ignite student involvement and significantly change a campus. As service providers we may find ourselves frustrated with our campus' failure to appreciate the essential perspective that disability offers, with its reactive approach to inclusion, and with students' hesitancy to use services or get involved. It may often feel like our advocacy is at odds with the mainstream and that we have too few resources (financial, personnel, and allies) to achieve comprehensive change. The experience at Syracuse demonstrates how we can alleviate these frustrations by embracing, both for ourselves and for students, a disability studies lens.

While many of our institutions don't have disability studies departments, Cory and her colleagues remind us that there are still ways in which we can capitalize on the potential of disability theory to encourage student activism and reframe concepts of inclusion and normalcy. The general lessons for the service profession that I take from the article include:

- Personally engage with disability studies theory through reading, research, and conversation. Disability scholarship offers perspectives that haven't been traditionally used to inform disability service practice but that offer a powerful impetus for professional and program growth.
- Consider how office policies, procedures, and messages frame disability consistent with disability studies theory... and if they do not, make changes. Intake processes, accommodation request/delivery procedures, communication

with students, faculty and administrators, and decision-making that may prioritize compliance over usability are all areas to examine. In each, is the "problem" framed as belonging to the student or an environmental barrier?

- Integrate progressive conceptualizations of disability into interactions with students
  - Foster a positive perspective on disability and resist traditional notions that stigmatize and segregate
  - Frame conversation not in terms of student "need" but in terms of environmental barriers
  - Respect student self-knowledge and expertise in identifying what works for them... sometimes over what the professional recommends
  - Provide opportunities for leadership and support students in those roles as their allies
  - Encourage students to engage with disability theory by collaborating with them in the development of progressive, campus-wide 'awareness' presentations and community development activities
- Encourage the inclusion of disability studies curriculum into the academy by engaging with faculty and administrators to explore and consider how disability is currently represented on campus. Disability studies content can be integrated into existing coursework, such as history, sociology, arts, and identity studies classes, or developed as new courses.

Syracuse's unique history and community and the presence of a "critical mass" of students involved in disability studies scholarship, were instrumental in setting the stage for change on that campus; however, the power of the article beyond case study is its demonstration of the empowering, transformational potential of disability theory for both students and the service profession.

### How to Crip the Undergraduate Classroom: Lessons from Performance, Pedagogy, and Possibility

### Ann M. Fox Davidson College

#### Abstract

My work in disability performance studies has taken place within the context of a small liberal arts college over the past decade, and has been more multifaceted than I had ever expected. This essay was originally conceived as part of a panel convened at the Society for Disability Studies Conference in honor of the publication of Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights (Lewis, 2006). I reference this volume, the first published collection of its kind, as a model and catalyst for defining strategies that educators wishing to incorporate disability studies into their campus community life, inside and outside of the classroom, might adopt. In the essay, I outline four such strategies and discuss them, using examples from my own experience: (a) "cripping" the canon, (b) "cripping" the curriculum, (c) enlisting your colleagues in the performance of disability, and (d) creating alternative on-campus performances of disability.

In 2006, Theatre Communications Group published Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights, edited by disability theater scholar Victoria Ann Lewis. Lewis's anthology was the first of its kind: As scholars of multicultural drama and women's playwriting had before her, she looked to the history and current landscape of activism and theater in search of a previously disregarded community, seeking a wider representation of disabled playwrights. While a burgeoning cadre of scholars in disability studies and theater was producing work studying the history, aesthetics, and political/performance strategies of disability theater, very few plays by disabled playwrights were actually available in published form for classroom study and theatrical production. This absence suggests all too well the place disability holds in the theatrical canon and in the larger society of which theater is representative: hidden in plain sight. Ironically, many of the narratives about disability in American culture, as in American theater, have been grounded in a dual, paradoxical identity: the simultaneous erasure and hypervisibility of disability. In other words, the only two options typically offered have existed as a "shut in" (behind the walls of the nursing home, rehabilitation hospital, institution, or private home) or life as a carefully defined and policed kind of representation (the freak show, the villain, the poster child, the heroic "supercrip," the inspirational figure, the miraculous cure, or the tragic but noble sufferer, to name just a few).

Theater fascinates disability studies scholars like me because it can move into the gaps between extreme subject positions to offer counternarratives, simultaneously moving the disabled bodies of actors and characters stage center in a way that models a new kind of social presence and visibility<sup>1</sup>. For me, a professor of dramatic literature with a specialty in disability studies, Beyond Victims and Villains (Lewis, 2006) is significant for obvious reasons; it enriches the body of available works written engaging disability. The late John Belluso, one of the most important playwrights in recent history, who wrote about and from within disability culture, once remarked in an interview, "I remember when I was a freshman, I went to the library and did a search for disability and theater, and it came up with zero hits. I was quite shocked, I started thinking, 'Who are the great disabled playwrights? Who are the ones that I'm going to learn from?" (Lewis, 2004, p. 38). Lewis's

<sup>1</sup> One need only look at the work of the Los Angelesbased theater companies Deaf West, or Blue Zone, for example, to become acquainted with the excellent work companies with disabled professional actors are doing to make this happen.

book offers the work of some of those playwrights, including Belluso himself, but for the purposes of this essay I want to suggest that it posits something more: a useful model for the teaching of disability studies that points to strategies possible for the dramatic literature classroom and others beyond it. In this essay, my larger project is to offer some strategies to colleagues who might feel a similar absence of disability in their own classrooms. Indeed, I offer these strategies not simply as a move toward the integration of disability, but in an attempt to convince others to do something even more radical: "crip" their own classrooms.

Disability studies scholar Carrie Sandahl (2003) has explored the intersection of the terms "crip" and "queer," describing how they both function to reclaim labels back from the pejorative, promote pride, express the fluid identities of the communities they represent, and work as verbs expressing contestation (pp. 27-28). In that last instance, "to queer" or "to crip" the known is to twist our expectations of it, defamiliarize it, and render it anew in ways that open up new kinds of possibility. That promise is built on denying the very binarism that would establish queer and crip identities as that against which, respectively, "norms" of sexuality and ability can be defined. Sandahl (2003) emphasizes, therefore, that the verb "cripping" can be used to describe the radical, edgy work of artists or activists that

spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects....[and to] expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity... (p. 37)

So it would seem that cripping is at the heart of any activist classroom concerned about advancing disability culture. And yet, if the term cripping is unfamiliar, how much more so must so-called "disability thinking" be to any of us who have not had to question the privileged position of our own bodily, cognitive, and/or pedagogical normalcy? And so, as a place to begin, I offer what I interpret as some of the some of the broad political and practical strategies of Lewis's text, stemming from its philosophy, aesthetic, and structure, as a sort of catalystcum-template.

Why use a drama anthology as metaphor and model for implementing disability studies across diverse disciplines? For those of us who teach or want to teach from a disability studies perspective, regardless of our field, the classroom represents a space of performance,

in which we might historicize disability, represent disability culture, interrogate traditional narratives of disability, and invigorate our own canons, whatever they may be. Because I teach drama as well as disability and literature, the examples I shall offer will be tied to my own classroom, but at their base are methods that could be adapted beyond the borders of an English or theater classroom. The strategies I discern in Lewis (2006) provide me a language to discuss similar ones I have used for integrating disability, performance, and pedagogy, and I describe them as the following: a) cripping the canon, b) cripping the curriculum, c) enlisting your colleagues in performance, and d) creating alternative on-campus disability performances. Each of these strategies, informed by and illustrated with examples from my own experience from over the past decade as a disability studies scholar and teacher, represent opportunities to invigorate pedagogy and invest our work and campuses with disability culture and disability studies. Make no mistake, there are implications of these strategies to which I still do not have the answers, important potential fissures to consider with which I will close this essay. I offer these ideas, as well as the dilemmas, as a starting point for those who wish to incorporate disability studies into their own teaching, no matter what kind of institution or level of familiarity with the field. Within the small liberal arts college (Davidson College in Davidson, North Carolina) that is my home institution, I have the advantage of being able to design courses that have a specific disability studies focus. But I do not presume that those reading this essay have such freedom. Therefore, some of these strategies can be implemented by those who perhaps do not have the ability, resources, or time to create a separate course.

#### **Cripping the Canon**

The educator who works from a disability studies perspective has to ask the same originating question as Lewis (2006) did in creating *Beyond Victims and Villains:* Who is not being heard historically, artistically, aesthetically, or theoretically, from a disability studies perspective? And just as importantly, how do we make the knowledge about and creative work of disabled people (including activists, educators, artists, scholars, and thinkers) available to our students within our classrooms? For me, that translated into the following question: Where could I locate the presence of disability in that which I was already teaching? As scholars and educators, we understand that every discipline has a body of knowledge considered canonical. Borrowing Sandahl's (2003) language, the question for us is how to "crip" that body of knowledge, challenge the presumption that it is set and unassailable, and seek out the literally and figuratively disabled directions it can take. Or to put it more plainly: How can we introduce disability as part of the identity of what we teach? "Cripping the canon" demands we recognize how disabled people have been important contributors to the content of our fields. It likewise demands we understand how disability might have been an integral part of how that knowledge was/is produced. Disability studies scholar Rosemarie Garland-Thomson (personal communication, January 15, 2009) has called this the "because of, not in spite of" way of thinking. How does disability shape knowledge and creation, rather than being that which production takes place "in spite of?"

One strategy is to educate ourselves about and be mindful of the contribution of disability culture to the content of our fields. For me, that translated into introducing plays from within disability culture into courses for which the addition they make would be significant. For example, within a course that is a survey of contemporary drama, I taught Lynn Manning's Weights (2003), a solo performance work that recounts how the African-American poet-performer, Manning, became blind and transitioned into his new life as a disabled person. Its presence importantly complicates and interrogates an understanding of both racial and disability identities by exploring their intersection through the popular theatrical genre of solo performance. Manning's work simultaneously satirizes and critiques the stereotypes and myths surrounding disability and black masculinity, but more so, points beyond them to those systems of the social construction of identity that produce them. His most pointed comment in this regard comes in "The Magic Wand," the closing poem he recites, which mulls over the divide others feel when trying to pigeonhole him as a black, blind man. Is he seen as, he wonders, "welfare-rich pimp" or "disability-rich gimp?" Ultimately, Manning (2003) observes, "my final form is never of my choosing. I only wield the wand [i.e., his cane]; you are the magicians."

Other plays similarly illuminate course ideas while reimagining them through a disability perspective. *Pyretown* (2004) was another a play I included in the contemporary drama course. An important work by Belluso (2004), it does what many other American plays do: engages the insidious side of relentless American individualism. If such individualism and self-reliance undergirds the myth of American identity, then it is no wonder that disabled people, made dependant on others if not afforded their right to equal access and accommodation, have been shunted to the periphery of history. Belluso's (2004) particular exploration of that dilemma is made by considering the crisis in health care in a poor town that has been essentially abandoned when an HMO closes the only hospital. Two characters, Harry (a wheelchair user) and Louise (a single mother) fall in and out of love as they struggle to make a life in a society that presumes only the survival of the economically and physically fittest. Belluso's work, like that of August Wilson, Cherrie Moraga, or Suzan-Lori Parks, negotiates the particular contradictions contained within the myth of America for members of minority communities. Like Arthur Miller or Eugene O'Neill, Belluso shows how the complex bonds of love suffer real damage from the weight of expectation imposed in a capitalist, success-centered society. In another course on "Queer Performance And/As Activism," I introduced excerpts from the work of queer/disabled solo performer Greg Walloch (F\*\*k the Disabled) (2001). Besides representing a particular kind of queer experience, including Walloch's (2001) work underscored that there are elements of the queer and disability experiences that can be likened and interrogated together, including passing and coming out.

To crip the canon might also mean cripping our rather canonical ways of reading, researching, and otherwise approaching and engaging an individual discipline, its core ideas and subject matter, introducing or framing them instead with a disability perspective. In dramatic literature classes, students learn to weigh the extent to which characterizations of disability approximate the moral or medical models. Students who, for example, might see the twisted body of the malevolent character Jacob Hummel as an innocuous example of August Strindberg's (1907) proto-expressionism in *The Ghost Sonata* (1962) are encouraged to recognize that character as part of a pervasive lineage of literary archetypes in which twisted body equals twisted mind<sup>2</sup>.

<sup>2</sup> The moral model of disability posits disability as an outer reflection of an inner moral state. Most commonly, that state is one of two extremes: extreme innocence or infamy (think of Charles Dickens' Tiny Tim vs. William Shakespeare's Richard III, for example). The medical model has largely displaced the moral model, and instead

Besides recognizing and cataloguing such depictions, however, we need to further invite students to consider their implications. How might the projection of anxiety onto disability be seen as anticipating larger modern concerns about identity and its construction? For example, when I teach Henrik Ibsen's revolutionary 1879 play A Doll's House in the context of a modern drama course, we spend time discussing the role of a character like the syphilitic Dr. Rank, and asking why illness needs to be visited on the body of this secondary character. We further consider why the intersection of disease and masculinity is so important to this play, given that the illness of three major figures (Nora's husband, father, and Dr. Rank) is necessary for Nora to practice her deception and become "empowered." Of what importance is it that Nora flirts with, and rejects, embracing an Ophelia-like insanity?

How, I might further ask in a contemporary drama class, do disabled bodies remain the locus for the projection of common cultural anxieties over 100 years later? For example, Alan Bennett's 2004 play The History Boys has as its main character a teacher, named Irwin, who toward the end of the play finally voices his desire for one of the young men he has taught. Almost immediately, without anything having happened between them, he is in an accident that leaves him in a wheelchair. How, we might ask, does this play manifest its anxiety about the queer teacher's body by disabling that protagonist? Another teacher, Hector, who has made ineffectual advances to some of his students, was played in the original production by Richard Griffiths, an actor of size. Is it easier for a director, then, to direct antipathy at the character and signal his immorality because he is obese? But disability's meanings are difficult, if not impossible, to pin down. Is it possible our sympathy is elicited through the pathos of this outsize character, whom no one, it seems, could imagine desiring? In any case, the question becomes moot, given that this teacher is killed in that same motorcycle accident, the disabled/queer body erased in the tradition of all kinds of anxiety-inducing characters, from the tragic mulatto

reads disability not as a marker of personality, but as pathology. In other words, disability is a problem located on the body of the impaired individual (not a societal problem or construction). The presumed desire of the sick person, and indeed the only desirable state, is to be cured. Otherwise, life is seen as at best a state of lack, and at worst, tragic and not worth living. The complexity of the actual lives lived in between the extremes of cure or kill remains unacknowledged. to the inhabitants of the celluloid closet. Ironically, however, even in work that foregrounds the body as a more complex site of contested meanings, there can still be a paradoxical use of the disabled body; it can slip easily from allied to archetypal (and therefore usually stereotypical). In class, I invite my students to fully weigh how minority playwrights use disability to give voice to their political and social oppression, and ask what the implications of such depictions are.

#### **Cripping the Curriculum**

Beyond Victims and Villains (Lewis, 2006) is able to posit new possibilities for an existing body of knowledge (e.g., how do we see the disability present in drama with which we are familiar?) But it also posits a new body of knowledge, inviting us to contemplate the question: What is the new disability drama, and why is it important to consider it for its own sake? Who are the important playwrights we need to know about, writers like Susan Nussbaum, John Belluso, and Lynn Manning? The collection's presence moves disabled writers into visibility, redefining the boundaries of contemporary and multicultural drama. For us as educators, that also means asking an analogous question about our own fields: What are the possibilities for new, disability-centered course design within the curricula of our disciplines? If opportunities for new course design are limited, what are the parameters of possibility for disability design within the context of what we already teach? And how can disability add new ways of defining knowledge?

For me, such opportunities have presented themselves in a number of venues. For example, I have designed two new courses for the English department at Davidson that are specifically disability studiesfocused: a survey of disability and literature, as well as a senior-level seminar on representations of disability in twentieth-century American drama. The disability and literature course, now in its third incarnation, evolved in a way that reflects the unfolding complexity of disability studies in the humanities. Initially, I started with a course that was a chronological survey that started with Sophocles' Philoctetes (407 BC) and concluded with part one (Millenium Approaches) of Tony Kushner's. In revising the course, I elected to move it away from a survey to an issues-based approach that reflected emerging questions being raised in the study of disability studies and literature. The version I teach now orients itself around different theoretical questions. For example, one week we might examine the social construction of disability; another week, we might look at how disability studies scholars have more recently queried the problematic elements of that construction. In considering critical questions shaped by disability theory (including important contemporary critical concepts such as "the stare," narrative prosthesis, and compulsory ablebodiedness), we are able to contemplate better what ideas about disability might have emerged from the interactions of authors and their audiences.

My own research on the presence of disability in American drama led me to develop a course on "Disability and American Drama," a course that broadened and complemented the teaching of drama I already did within my home department through courses on feminist, queer, and multicultural drama. That senior-level survey allowed for the close re-examination of the representation of the image of disability. In the course, we considered how disability limped, hobbled, and rolled its way onto the stage from the earliest days of American drama, including its omnipresence during nineteenth-century melodrama as marker of innocence and infamy. The premise of the course was that disability was integral to drama's evolving role throughout the twentieth century in reflecting anxiety and excitement over cultural shifts involving gender, race, sexuality, and class. Disability's presence in an increasingly socially conscious drama went beyond its usual role as mere metaphor for moral fortitude or failure, beyond its usual treatment as only medical pathology. Dramatic representations of disability across the century also prefigured today's playwriting from within disability culture, establishing a nascent "disability aesthetic" of drama.

I also have adapted courses I already teach with a disability studies emphasis. I teach a section of freshman composition every year; in multiple semesters, I have designed the course to have a disability studies core, titling it "Extraordinary Bodies." The course emphasizes writing and research skills Davidson students need, but also integrates that with an introduction to the history of disability, an understanding of disability activism, and a primer on disability culture. The course encourages students to rethink their own encounters with the performance of disability. This leads to fascinating stories of all kinds, ranging from students used to inspirational models, to students who have had disabled members of their families and never understood how to define their experience as strong and worthwhile. An introduction to literary analysis class that I regularly teach

introduces students to different schools of theoretical thought. I regularly include disability studies as one of the approaches to literary criticism I deem essential for students to learn. The trick to "cripping the curriculum," then, is not to get caught up in thinking you will need to utterly transform the knowledge of your field, but rather, perhaps see it anew. What are the ways disability might be "hiding in plain sight" in your field, and how can you as an educator underscore them for yourself and your students?

What never ceases to amaze me is how quickly students turn into resources for new disability performances, continually connecting me to sources, stories, and connections from their classes and popular culture interests. It is a truism of disability studies that once you begin to think about it, disability starts to appear everywhere you look. It has been no less true in these classes. Students, for example, express amazement that they have never noticed disability tropes in favorite works. One student, for example, in my senior-level Disability and Literature class was shocked to realize how completely she had missed the images of disability that permeate Toni Morrison's novel The Bluest Eye, even though she had read the work three times. In no other subject have I had the sheer range of students maintain interest in a subject once beyond the walls of my classroom. Whether sending me a recent news story on disability, an image of disability art, or seeking my advice about their own disability-related projects, students have remained "infected" in a way that suggests they are exploding their own canons of knowledge in the fields and disciplines they enter. The liberatory potential of cripdom appeals in part because the once unknown is becoming known, but also, I think, because they understand the revolutionary potential of that act of cripping their own understanding.

# Enlisting Your Colleagues in the Performance of Disability

Part of the purpose of a work like Beyond Victims and Villains (Lewis, 2006) is to present resources, inviting others to embody disability on stage by offering the literal scripts with which to do it. As educators, we can adopt a similar strategy: What are the ways we can invite others to engage with a real, palpable performance of disability? So often, the performance of disability at our home institutions is as limited as its historical stage representation. Disability is the "problem" that must be accommodated with extra time or an extended deadline; it is the object of charity, the subject of students' fundraising efforts; or, it is disembodied altogether (for example, it might be part of an ethics or a science class, but not looked at as a socially constructed identity, culture with its own history to be studied, or embodied existence that has pleasure as much as pain). The disability studies educator, even the one who may not be able to create complete classes on disability studies, can still enlist colleagues and students in counteracting these traditional performances, substituting them with alternative views of disability. This can be done through actively seeking out opportunities to make others see the presence of a very different definition of disability within their own subject areas.

What are some of the ways I have done this at my home institution? Because my liberal arts college has a relatively small faculty, I've been able to make colleagues in other departments aware of what I do as a disability studies scholar. This has led to opportunities to guest teach in other colleagues' classes and link issues and ideas in those courses to a disability studies approach. Some of these performances have taken the following shape:

- 1. A colleague teaches a first-year composition course on the cultural history and social meanings of toys. For one class session, I took my own collection of disability toys over to the class for a "show-and-tell." These toys range from Fisher-Price Rescue Heroes (with laserequipped wheelchairs) to X-Men Professor X figures (also in a tricked-out wheelchair) to disability Barbies (both "Sign Language Teacher Barbie" and three different incarnations of "Becky," Barbie's disabled friend). The toys enabled me to speak about the intersection of gender and disability (all the toys seem to overcompensate for supposedly weakened masculinity or femininity as a result of disability). They also allowed me to scrutinize, with the students, evolving narratives about disability (for example, disability Becky's incarnations that move from sentimental poster child to overcoming supercrip).
- I have visited classes as wide-ranging as a political science course on the "American Dream" and a senior-level musicology seminar. In the former, I spoke about the impact of the myth

of individualism on the disabled person. In the latter, I had an exchange with musicologist and disability studies scholar Neil Lerner about the presence of disability in music history and musical composition.

3. As a result of a collaboration with our on-campus art gallery, in 2009, I co-curated two exhibitions at Davidson entitled RE/FORMATIONS: DISABILITY, WOMEN AND SCULPTURE and STARING. I gave tours of the exhibitions to widely varying class communities. For example, for RE/FORMATIONS, I spoke to groups of students from a biology class on genetics and an English literature class on literature and medicine. I was able to speak with the students about the implications that the representation of disability in the art exhibit had for the kind of scholarly and scientific work they themselves were doing. In both exhibits, students were also able to see theoretical and scholarly ideas about the construction of gender and the body translated through a visual medium, making those concepts more widely public and accessible.

Once invited to see the presence of disability within their own disciplines, I have found my colleagues themselves have found a wide range of ways to engage disability. Some have mentioned to me plans to create their own disability-related projects. Others (one in the social sciences, and one in the natural sciences) have discussed with me the possibility of team teaching courses in disability across our fields. Colleagues within my department have worked with students on honors theses that have taken a disability-studies related focus. Colleagues in the arts have discussed with me the implications of disability for training and performance. My point here is that a disability presence quickly manifests itself exponentially, once others are invited to see how it is at the heart of their own work.

#### Creating Alternative On-Campus Performances of Disability

It is not uncommon for me to get the following suggestion, at the end of a semester-long disability studies course, on evaluations or from students directly: Why not have exercises akin to those "sensitivity training" ones that simulate blindness for a day, or being a wheelchair user? I find it an interesting and reasonable question. After a semester of attuning themselves to disability history, politics, culture, and representation, the mostly nondisabled students who take my courses feel a sense of urgency, and a desire to make the disability experience more material for themselves and others. And yet, I refuse to do such exercises (for reasons that are familiar and debated within the disability studies community) because they cannot approximate the experience of having lived with a disability beyond the one day of the exercise. These exercises deny the wide-ranging and fluid nature of disability as an identity, and they emphasize disability as a pitiable, tragic, and difficult position, completely removing any possibility that power or pleasure could exist as part of disability identity as well. They also do not address the fact that ableism can take on subtler, more multivaried forms than lack of access. How, for example, do such exercises challenge the beliefs of students or professors who believe extra time on tests or papers to accommodate learning disabilities amounts only to "special treatment" at best, or a "disability con" at worst? And yet, performance is a powerful thing. Where can we enter into the void between charity fundraisers and crip-for-a-day exercises? Beyond Victims and Villains (Lewis, 2006) deploys multiple performances to complicate and shift the stage representation of disability. But how can we create opportunities beyond the classroom for students to perform disability in a new and wider variety of ways on our campuses?

One way to do this is through using extant campus speaking series and public lecture funding opportunities to feature disability-related topics. This is easier than it sounds. Disability is so intertwined with culture and history, that topics already of interest and relevance to intellectual communities almost invariably are interconnected with disability in some ways. We can ask ourselves: What might such opportunities to highlight the disability aspect of an important historical or cultural moment be? For example, Simi Linton, a writer, scholar, disability arts consultant and activist, brought the 1999 documentary film Liebe Perla to Davidson's campus for a screening and discussion. The film, which documents the search for evidence of how the short-statured members of a Jewish family had been victimized by Josef Mengele, is a powerful historicization of how disabled people were among the first victims of the Holocaust. On a campus where the literature and history of the Holocaust

are already taught, this film was an important reminder to remember those who were among its first victims.

The Anarcha Project, a research and performance collective, represents another opportunity for interconnection, this time between history, ethnic studies, women's studies, and disability studies. I brought this performance collective to Davidson for a week-long residency. Made up of scholars and artists, it purports to revive and recreate the stories of three slave women on whose bodies the "father of gynecology," J. Marion Sims, performed experimentation in the name of medical advancement (Kuppers, 2008). Through questioning the construction of medical and racial history, the Anarcha Project adds its counternarrative to medical history, one that questions the very nature of archiving and epistemology itself. What does it mean to reconceptualize, through disability, how we create and archive knowledge in the classroom and beyond? When the members of the Project came to campus, they spoke to English literature and political science classes about the nature of their research, and how they were attempting to resuscitate the reality of these women's lives and pain. Working within the framework of an extant script, they conducted performance workshops, in which Davidson students were invited to embody the stories of Betsy, Lucy, and Anarcha, investigating what it meant to recount disability history (and rewrite American history) through dance and movement.

The Anarcha Project and Liebe Perla further suggest the rich possibilities inherent in using on-campus arts events to showcase disability culture and create a dialogue within a community. For example, I brought Joan Lipkin, founder and director of The DisAbility Project in St. Louis, to lead an artistic residency and make community-based work similar to that she creates in her own community. She worked for a week to make a performance piece addressing issues of disability at Davidson College; the subject matter and performers both came from the Davidson student body. Petra Kuppers and Johnson Cheu both shared their own work as disabled poets, reading work for Davidson audiences that moved disability imagery out of the old metaphors and into new expressions of embodiment. Perhaps the most exciting example of the new disability arts that found an expression on the Davidson campus were the two 2009 exhibitions in Davidson's Van Every/Smith art galleries entitled RE/FORMATIONS: DISABILITY, WOMEN, AND SCULPTURE and STARING. These were the culmination of a year and a half of collaboration between myself and Jessica Cooley, assistant gallery director, as co-curators. Together, we worked across the disciplinary boundaries of art and literary study to create art exhibits that examined disability as a cultural identity. In the case of RE/FORMATIONS, we examined in particular what it meant when female and disability identities intersected<sup>3</sup>. These identities, while not identical, hold so much in common. Women and the disabled have been relegated to secondary status in society, cast as those excessive and unruly bodies against which the normate defines itself. The exhibit contained both sculptures and installations by turns contemplative and confrontational, and explored a number of questions: What is the new disability art? How can art make material the disability experience? If an artist's mobility or intentionality do not match what we think of as "typical," what possibilities does that open up for invigorating how we understand art itself? In the case of STARING, we built on the theoretical ideas expressed by feminist disability studies scholar Rosemarie Garland-Thomson in her 2009 book, Staring: How We Look. Garland-Thomson (2009) avers that staring is an opportunity for starer and staree to connect across difference. We included in the exhibition works by visual artists such as Doug Auld and Chris Rush, whose images Thomson posits model this kind of opportunity. We also drew works from the Davidson permanent collection, including works by canonical artists such as Goya, Hogarth, and Rembrandt. This time, however, they were featured as part of a visual discussion of a theoretical concept (i.e., "the stare"). Disability became public in that exhibit in multiple ways: through the invitation to re-see works we already had through a new critical lens, and through this visual expression of what has been so importantly theorized and argued by Garland-Thomson (2009).

#### A Closing Strategy: No Closure

The strategies outlined here for creating disability pedagogy as suggested by the aesthetics, format, philosophy, and impact of *Beyond Victims and Villains* (Lewis, 2006) are ones I have found sustaining and continually surprising. And yet, performance is necessarily ephemeral, incomplete, and finite by its very nature. Not surprisingly then, these various methods of performing disability still leave room for questions, complications, and inconsistencies. If disability studies is premised on the denial of the normate as a force to contain, define, and quantify, then it seems appropriate that I leave this list of strategies open-ended. The process of establishing disability studies on any campus is necessarily an ongoing one particular to that community. Therefore, I would like to close by *resisting* closure, suggesting questions and complications that have arisen as I have engaged these strategies. Disability studies remains a subject that causes people discomfort, for a variety of reasons: boundaries between disabled/nondisabled identities are called into question; stigma is a powerful force; many people lack exposure to disability; and even once people become attuned to disability, there can be an uncertainty on their part of what to do next. But ultimately, I think these uncertainties are a sign of the productive discomfort disability studies can create in our own educational communities.

For example, anyone who does disability studies, with the exception of a very few employed at schools with such programs, will most likely be the only one (or one of a small number) doing such work on their campus. In one sense, this is not at all different from having an academic specialty. But where it is different is that disability is also an issue of diversity and accommodation on our campuses, not simply an academic issue. Often, I find myself being contacted by faculty or staff needing advice on providing accommodation. Becoming a "go to" person on disability has promising and problematic political implications. It has allowed me to advocate or offer advice when I can, and has certainly changed my viewpoint, making me see from a disability perspective what salient issues for disabled Davidson students might be, ones that I as a nondisabled person might never have expected or anticipated otherwise. However, it is a reminder of the fact that disability is still thought of as monolithic; what might be an answer in one situation might not be in another. I cannot claim to speak for disability culture, let alone represent/inform all possible contingencies. I have realized it is important to admit when I do not know something, not so much to let myself off the hook, but to force the institution to shift and locate that knowledge in useful ways.

Indeed, as a nondisabled scholar who is very much a participant in disability culture and an ally of disability activism, my own embodiment further poses questions

<sup>3</sup> To see the online exhibition catalogue for RE/FORMA-TIONS: Women, Disability, and Sculpture, go to www. davidson.edu/reformations. To view the online exhibition images from *STARING* go to http://www.davidson.edu/ cms/x39519.xml

that are important to consider. As a nondisabled person, what risks do I run in teaching disability studies? What, exactly, is the nature of my performance? What does it mean to implicitly speak for disability culture as a disability studies educator? Am I a member of disability culture? Where might I be falling into paternalistic traps of my own? It is important to feel good, and rightly so, about students you have connected to disability culture. I am very proud, for example, that some of our students formed a disabled student group. However, I have learned that an important part of countering paternalism is recognizing that sometimes disabled students will not embrace disability culture or identity. For me, that is akin to my own late arrival to feminism, a term I would never have embraced at my students' age. What is sometimes more difficult is being confronted with a student who embraces a kind of contradictory consciousness. While I have worked with students who have embraced fierce crip pride, I have worked with others who, while intellectually understanding passing and overcoming metaphors, still actively replicate ableist structures in their own life and work, in essence playing the "good crip." It is hard to fault them, since this kind of subject position is still heavily rewarded in society. I also cannot know the full circumstances of any one person's life or sense of their own disability identity. What I can do is realize that advocacy and education is larger than any single student. Some are ready for these conversations, others are not quite there yet (but hopefully may be one day). The late disability rights activist Harriet McBryde Johnson (2005), in her memoir Too Late to Die Young, acknowledges this difficulty, yet emphasizes the importance of sharing community with those who are ready, of preaching to the converted in the ways that we can.

What is perhaps most exciting for me is that I am continually having conversations about disability on my campus with students, staff, and colleagues. Disability is, after all, an identity that touches everyone, and if we are nondisabled, one we will all enter if we live long enough. The meaning of disability remains amorphous and undefined enough in our society that sometimes well-meaning others mistake my work for an interest in rehabilitation, charity, or sentimentality. But to me, such mistakes become opportunities to bridge the medical and moral models with disability culture and its much more real, multivaried, and wonderful world. My purpose with all these strategies, then, is ultimately to blur the divide between disabled and nondisabled, to multistream rather than mainstream, to complicate that binary rather than eradicate differences in some kind of elusive or illusory search for "universals." What lies beyond victimhood and villainy, after all, are vitality and invigoration. Re-reading the representation of disability can posit fresh and exciting new ways to understand how our own views of the world are constructed, an understanding that can have empowering implications for bodies of all kinds: "victims," "villains," and the more realistic, lived subject positions in between.

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# About the Author

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### Professional Perspective Ward Newmeyer Dartmouth College

Twenty-some years ago, a colleague noticed me at a restaurant reading Zola's *Missing Pieces* (1982). Did I, he teased, ever stop working? I objected that it was not really work. I was a practitioner, not a scholar. "Work" reading was practical, perhaps something about organizing interpreter services or grant writing. *Missing Pieces* was not the sort of thing I should read on company time. I didn't fully believe that at the time, but my response was instinctual.

Disability studies was a nascent field that seemed to have little overlap with disabled student services professionals. That overlap is much greater now, and Ann M. Fox's How to Crip the Undergraduate Classroom: Lessons from Performance, Pedagogy, and Possibility (2010) is a delightful springboard for thought about how disability studies, disability services on campus, and students can reinforce one another. Professor Fox outlines four strategies that disability studies scholars in any discipline might employ to ". . . incorporate disability studies into their campus community life inside and outside of the classroom . . . . " (p. 40). She terms this "cripping" the classroom, and goes on to describe cripping the curriculum, the campus environment, and even the students themselves<sup>1</sup>. I offer observations relevant to my work serving disabled students and advocating for an inclusive campus . . .

Disabled Student Services (DSS) professionals can greatly benefit from staying connected with disability studies and using it to inform our work. Especially in her discussion of "cripping," Fox notes the importance of turning dominant-paradigm thinking about disability on its ear, in a manner that (quoting C. Sandahl) "spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects . . . [and to] expose the arbitrary delineation between normal and defective and the negative social ramifications

- 2. DSS professionals are well-poised to supplement students' disability studies education. This is consistent with the "student development" underpinnings of most modern student services in higher education. We often have the most interpersonal and disability-specific interactions with students and, with some, the best opportunities to engage them as they consider their identities as disabled people in ablist societies. These interactions help us think through our roles too, as we learn from the students and mutually ". . . understand the revolutionary potential of cripping [our] own understanding" (p. 43).
- 3. In a similar vein, students with disabilities who are themselves engaged in disability studies can be powerful agents for change. It is often they-not we-who can most quickly and powerfully influence change amongst the faculty. Their common disability studies endeavors can help strengthen cohesiveness without compromising individuality.
- 4. Disability studies helps us consider roles and issues for the many nondisabled DSS personnel on campuses. To paraphrase the questions that Fox poses for herself:

As a nondisabled person, what risks do I run in my work? What, exactly, is the nature of my role? What does it mean to implicitly speak for disability culture/issues as a professional in the field? Am I a member of disability culture? Where might I be falling into paternalistic traps of my own? (p. 47)

And yes, I now would urge DSS professionals to read Zola's *Missing Pieces*!

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<sup>1</sup> On page 40, Fox ably defines the "crip" noun and verb terminology, in the context of honoring and incorporating disability aspects in environments and the learning experience of her students – hence, "cripping the classroom." Disability Services professionals will need to carefully analyze, perhaps even strategize, the circumstances and contexts in which we might consider using such powerful terminology, and we should carefully gauge our audiences' readiness as well as our own authorities for using it.

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## Disability Services' Standards and the Worldviews Guiding Their Implementation

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#### Abstract

This paper presents a study that incorporated an Internet survey to analyze disability-related perspectives held by higher education's disability service providers in the implementation of program standards. Incorporating disability studies scholarship, the quantitative study used the constructs of individual, social, and universal approaches to service delivery as a looking glass. The study's investigation involved a sample of disability service providers who held a membership in the Association of Higher Education And Disability (AHEAD) during fiscal year 2007. In general, findings indicated participants were more likely to deliver services guided by an individual approach, thereby determining the individual's "deficit" and accommodating the disability. However, findings also indicated that, to some extent, participants had awareness of and sometimes utilized either social or universal approaches in their service delivery. This manuscript concludes with a discussion of implications for disability studies, disability services, AHEAD, and service professionals.

The present study sought to understand perspectives held by higher education's disability service providers relative to disability and/or students with disabilities and how such perspectives became evident in the implementation of best practices. Although the intention of the Association on Higher Education And Disabilities (AHEAD) standards is to improve the quality of services provided to students with disabilities attending colleges, the standards lack a contextual anchor, permitting the utilization of diverse and antithetical worldviews in their implementation. Using the work of disability studies scholars, three disability worldviews and their applications in the provision of disability services in higher education were considered to explain how these perspectives have maintained the status quo or have re-framed disability. For those reasons, the historical development of disability services, the legislation affecting its development, and also ideas and frameworks developed by disability studies scholars were reviewed. Ultimately, the researcher sought to learn how disability service providers' perspectives of disability and/or disabled people have percolated into service delivery practices.

Disability services in postsecondary education have

undergone many changes, including an increase in the population of disabled students from 2.2% in 1978 to 17% in 2000 (Gajar, 1998; National Center for the Study of Postsecondary Educational Supports [NCESPES], 2002), legislative mandates prohibiting discrimination against people with disabilities (Rehabilitation Act, 1973), and the professionalization of disability services (Dukes & Shaw, 1999, 2001; Madaus, 2000; Prize, 1997; Shaw & Dukes, 2001, 2005, 2006; Shaw, McGuire, & Madaus, 1997). In addition to experiencing the stress of rapid growth and change, the provision of disability services in postsecondary education did not enjoy the benefits of having standards delineating the essential components for the job. Section 504 of the Rehabilitation Act (1973) and the Americans with Disabilities Act (ADA, 1990) did not establish standards or dictate the manner in which disability services in postsecondary education should be implemented. Regardless, the development of such enactments was the result of societal forces, changes in attitudes, legislation, and student advocacy (Madaus, 2000). Meanwhile, disability service providers/researchers have developed standards (Prize, 1997; Shaw & Dukes, 2001, 2005, 2006; Shaw, et al., 1997) as a framework to guide service provision.

AHEAD's standards are a research-based approach of informing stakeholders of the ethical, professional, and programmatic requirements needed to achieve equal access for students with disabilities who are attending higher education institutions (Prize, 1997; Shaw & Dukes, 2001; Shaw, et al., 1997). The standards have provided professionals with clear indicators of the skills needed to do their job and add important elements necessary for both quality service delivery and evaluation. These empirically developed standards have also allowed postsecondary disability service providers to move their profession to a best-practice model, having evolved from one in which an agent was in charge of implementing legislative mandates that did not delineate state-of-the-art services (Brinckerhoff, Shaw, & McGuire, 1993).

Disability service professionals do not enjoy the standardized training of other professions and come from a variety of disciplines (Brinckerhoff, et al., 1993; Madaus, 2000). Therefore, standards are necessary to ensure that disability service providers adequately serve students with disabilities (Brinckerhoff, et al., 1993). Brinckerhoff et al. (1993) explain that the creation of standards of best practice could prevent the erosion of legislators' intentions because courts would be more likely to follow the lead of established professionals at the vanguard of best practice. In addition to these standards, other factors related to participation of students with disabilities in higher education pertain to the passage of federal legislation regarding civil rights and the education of persons with disabilities.

Prior to Section 504 of the Rehabilitation Act of 1973, services for students with disabilities were limited to a few institutions. Some of these programs were created in conjunction with vocational rehabilitation services to meet the needs of war veterans with physical disabilities, yet discrimination on the basis of a student's disability was common (Madaus, 2000). Section 504 was the first civil rights law that challenged the status quo by prohibiting any program receiving federal dollars, including institutions of higher education, from discriminating against "otherwise qualified" individuals with disabilities seeking entrance to such programs (Rehabilitation Act, 1973). Other influential legal mandates that further impacted services offered at colleges and universities were the Education for All Handicapped Children Education Act of 1975, commonly known today as Individual with Disabilities Education Im-

provement Act (IDEA, 2004), and the Americans with Disabilities Act (ADA, 1990). IDEA (1975) stands as a promise for a free and appropriate public education, using tools such as the Individualized Education Programs (IEP; K-12) and transition plans for all students with disabilities. Adding to the requirements set in these two legislations, and because the discrimination clause was not contingent upon the program receiving federal funds, the ADA broadened the reach of Section 504. However, court decisions, not postsecondary disability service professionals, have continued to redefine who is protected by the law, what are essential components of a program, and the role of mitigating circumstances (Madaus, 2000). In addition to the standards and laws created which affect the implementation of services, a discussion of the potential role disability studies could and should play in the provision of services was included.

An emerging discipline, disability studies serves to theorize about the experience of disability, using the voices of the individuals living under the oppression of disablement (Abberley, 1987; Oliver, 1990). The discipline considers the environment instead of the impairment in attempting to understand what contributions the environment makes in limiting the ability of individuals to function as active members of society (Hahn, 1985, 1987; Oliver, 1990; Zola, 1989). Both Oliver and Hahn argued that the disadvantages experienced by persons with disabilities are due to conditions (the environment) that reside outside the individual's body. Therefore, lower socio-economic statuses as well as poor labor force participation are products of a society that continues to marginalize disabled people. Oliver (1996) has explained how disability is a product of our materialist society, one that does not take into consideration the needs of those living with disabilities. Hahn (1985, 1987), like Oliver, emphasized that society is responsible for the disadvantages experienced by persons with disabilities; however, he also argued that the acquisition of civil rights by this group could aid in their emancipation. The acquisition of civil rights should prevent persons with disabilities from being relegated to a subjugated status (Hahn, 1985, 1987).

Like Hahn and Oliver, the late sociologist, Irving Zola (1989) argued that disability resulted from the poor fit between impairments and societal environments. His position reaffirms the role of the environment and, like Hahn, Zola argued that policies played an important role in the oppression or emancipation of persons with impairments. His greatest point of departure from Hahn and Oliver was his view that disability is not a dichotomous concept with a person either having a disability or not. Instead, Zola (1989) emphasized that all individuals fall within a continuum that represents all the levels of ability found among human beings – a universal dimension of the human experience. Zola noted that the ranges of ability among humans vary widely and, therefore, society should adopt measures that are universally compatible with those variations. Reframing disability through policies that provide the greatest level of flexibility possible should prevent the marginalization of individuals falling at the lower end of the ability spectrum.

Understanding how these perceptions are reflected in disability services in higher education could help service professionals determine the implications of their approach. This knowledge allows the service provider to evaluate their own biases and also their personal impact on service provision. Having the means for evaluating the hidden assumptions behind service provision and having different perspectives to compare offers the potential for articulating a new vision of service delivery, one that could fully embrace the expectation of eliminating discrimination against students with disabilities. Lastly, an understanding of the different perceptions about disability may help frame the AHEAD standards and ensure the provision of state-of-the-art services. Therefore, this study analyzed implementations of the AHEAD standards to understand the intersection between service provision in postsecondary education and current perspectives of disability. For the present study, the following hypotheses were explored:

- Disability services personnel in higher education utilize/frame an individual approach more often than either a social or universal approach when implementing the AHEAD program standards.
- 2. Disability services personnel in higher education are guided by a mixture of ideas reflecting all three approaches.

The following question was answered:

 Are there significant differences in the utilization of an individual/medical, social, or universal perspective when framing the implementation of standards of best practice used by disability service providers in postsecondary education?

#### Method

#### **Key Measurements**

Through an Internet survey, data was collected to understand the prevalence of an individual/medical, social, or universal worldview (Figure 1) of disability in the implementation of eight core areas encompassing the AHEAD's program standards. This study established a baseline and significant group differences by measuring "some unknown characteristic of a population" (Czaja & Blair, 2005, p. 21), in this case, the disability service providers' perceptions of disability. The data collected from this sample assisted in the description of the phenomenon studied (Czaja & Blair, 2005) and provided useful data for structuring future disability services' policy. The study consisted of a group of disability service providers in the United States who were AHEAD members during the fiscal year 2007 (See Tables 1 and 2 for descriptive statistics).

#### **Selection of Study Respondents**

The researcher randomly targeted disability service personnel from a range of colleges and universities. The sample was chosen to be representative of those AHEAD members responsible for the implementation of AHEAD program standards. To determine the sample size, the researcher followed the formula used by Czaja and Blair (2005) to obtain the sample size of 215 participants. To account for non-responses, this sample size was increased 100%, therefore the final sample size included 430 AHEAD members. The survey response rate achieved was 30%, somewhat lower than specified by the literature (Bradburn, Sudman, & Wansik, 2004; Czaja & Blair, 2005; Trochim, 2001), and response rates from other studies conducted with AHEAD members (Harding, Blaine, Whelley, & Chang, 2006; Sneads, 2006). However, since this study used a simple random sample of disability service providers, the study maintained the external validity required generalizing to the overall population of AHEAD service providers (Bradburn, et al., 2004; Czaja & Blair, 2005; Trochim, 2001). Once the sample size was determined, participant selection began via a randomized procedure. After purging the list provided by AHEAD of private companies, governmental service institutions, and private citizens, the researcher kept only a list of postsecondary academic institutions. A selection of 430 institutions was randomly selected from the list. Institutions from this shorter list having more than one member underwent

#### **Individual Approach**

Looks at the individual and seeks strategies that will compensate or level the playing field

#### **Social Approach**

Looks at the environment and seeks strategies to remove barriers

#### **Universal Approach**

Looks at the design and seeks to develop an environment inclusive of the largest number of persons possible.

Figure 1. Three Approaches to Disability Service Provision

#### Table 1

Individual Characteristics

| Disability    |        | Gender        |        | Main Responsibility |        | Years of Experience |      |
|---------------|--------|---------------|--------|---------------------|--------|---------------------|------|
| No            | 31.85% | Male          | 17.78% | Director            | 51.85% | Range               | 1-34 |
| Yes           | 68.15% | Female        | 82.22% | Service<br>Provider | 45.93% | Mean                | 8.61 |
| No            | 0.74%  | No            | 0.74%  | Neither             | 0.74%  | -                   | -    |
| Response<br>- | -      | Response<br>- | -      | No<br>Response      | 2.22%  | -                   | -    |

another selection round in which only one of the eligible AHEAD members was randomly chosen.

#### **Survey Instrument**

The Internet survey was pre-tested with 10 individuals unfamiliar with the project. Results from this test confirmed the survey was compatible with screen reading technology. The test took approximately 10 minutes to complete and questions were clear and understandable. The survey constructs were discussed and refined by submitting the instrument to experts in different content areas. The instrument (See Appendix A) provided macro-level evidence on approaches used by disability service providers in implementing the AHEAD program standards. The survey contained general demographic questions to allow for investigation of group differences. Primarily, the survey asked participants to rank the implementation of each of the core program standards in order of importance, using three worldviews: individual/medical, social, or universal.

The survey was constructed with a screening question to determine if the participants had been responsible for implementing each of the components. If the screening question was answered in the affirmative, respondents were then directed to a question that explored a specific standard along with the priority rank the participant assigned to each of the worldviews. Participants were not asked if they used one of the worldviews directly. Rather, for each core element participants were asked to choose one of three action statements that described an action representing each of the three worldviews. The action statements were carefully crafted and communicated key elements of the specific worldview, such as remediation, rights, and/or environmental design. This part of the study only established a

| Individual's Educational Chara | acteristics |
|--------------------------------|-------------|
|--------------------------------|-------------|

| Educati  | onal Level | Educational background    |        |  |  |
|----------|------------|---------------------------|--------|--|--|
| Associat | e 0.74%    | Counseling                | 20.74% |  |  |
| Bachelor | r 8.89%    | Higher Education          | 17.78% |  |  |
| Masters  | 73.33%     | Psychology                | 8.89%  |  |  |
| Doctorat | te 14.81%  | Rehabilitation Counseling | 13.33% |  |  |
| Other    | 2.96%      | Social Work               | 4.44%  |  |  |
|          |            | Special Education         | 17.78% |  |  |
|          |            | Other                     | 17.78% |  |  |

baseline, regarding the perceptions of disability service providers. A second manuscript, still under preparation, documents qualitative data examining how participants' actions match their perceptions.

#### **Data Analysis**

This study's data was aggregated to help identify the utilization and prioritization of services depending on whether disability service providers in postsecondary education employed an individual/medical, social, universal, hybrid approach, or philosophy while implementing AHEAD's standards (Table 3). These patterns were studied in relationship to selected demographic variables with the purpose of understanding if there are significant differences among different groups (e.g., gender, years of experience).

#### Results

This section of the study focused on the prevalence of the three ideologies during implementation of the AHEAD's program standards (see Table 4). The eight core areas are advocacy; access; consultation; academic accommodations; promotion of independence; policy development/review/revision; and disability professional, professional development, plus a composite variable accounting for all core components. Nonparametric statistics were utilized because the data being analyzed was categorical in nature. Therefore, the aim of this study was to find patterns rather than absolute values or measures of central tendency (Trochim, 2001).

A Friedman test was utilized to determine if there were significant differences on the ranking of the three ideological approaches when implementing the AHEAD program standards. This test showed that each of the eight core areas, as well as the composite variable, had significant results (see Table 5). Therefore, subsequent Wilcoxon-related sample post hoc analyses were conducted to understand the differences. The results of this post hoc test showed the following differences:

- Participants ranked using an individual approach significantly higher than a universal approach for the following eight components: advocacy (z = -4.908, p =.000), access (z = -3.852, p =.000), consultation (z = -2.247, p =.012), accommodations (z = -8.754, p =.000), policy (z = -4.654, p =.000), professional (z = -5.486, p =.000), professional development (z = -1.657, p =.049) and the composite (z = -6.455, p =.000) components of the program standards.
- · Participants ranked using an individual ap-

Ideology Rankings

| Dependent Variable       | Question                             | Test              |
|--------------------------|--------------------------------------|-------------------|
| Advocacy                 | Are there significant differences in | Friedman/Wilcoxon |
| Promote access           | the utilization of an                |                   |
| Consultation             | individual/medical, social, or       |                   |
| Accommodation            | universal perspective on the         |                   |
| Promoting independence   | implementation of the program        |                   |
| Policy development       | standards?                           |                   |
| Disability professional  |                                      |                   |
| Professional development |                                      |                   |
| Program Standards        |                                      |                   |
|                          |                                      |                   |

#### Table 4

Breakdowns of Rankings by Ideology

|              | Indivi | dual | ·    | Social |      |      | Unive | rsal |      |
|--------------|--------|------|------|--------|------|------|-------|------|------|
| Priority     | High   | Mid  | Low  | High   | Mid  | Low  | High  | Mid  | Low  |
| Advocate     | 58.2   | 25.4 | 16.4 | 20.9   | 41.8 | 37.3 | 20.9  | 32.8 | 46.3 |
| Access       | 42.7   | 33.9 | 23.4 | 31.5   | 57.3 | 11.3 | 25.8  | 8.9  | 65.3 |
| Consult      | 58.1   | 29.0 | 12.9 | 5.6    | 25.8 | 68.5 | 36.3  | 45.2 | 18.5 |
| Accommodate  | 85.0   | 9.8  | 5.3  | 8.3    | 49.6 | 42.1 | 6.8   | 41.4 | 51.9 |
| Independence | 32.1   | 26.6 | 40.4 | 18.3   | 42.2 | 38.5 | 48.6  | 30.3 | 20.2 |
| Policies     | 54.1   | 25.4 | 20.5 | 23.8   | 53.3 | 23.0 | 22.1  | 21.3 | 56.6 |
| Professional | 68.1   | 24.4 | 7.4  | 3.7    | 40.0 | 56.3 | 28.1  | 35.6 | 36.3 |
| Development  | 53.3   | 33.3 | 13.3 | 1.5    | 36.3 | 62.2 | 45.2  | 31.1 | 23.7 |

Participant response frequency percentages (n=135)

| Component                                | Chi-square | DF | Ν   | Р    |
|--|------------|----|-----|------|
| Advocacy                                 | 35.64      | 2  | 134 | .000 |
| Access                                   | 29.05      | 2  | 133 | .000 |
| Consultation                             | 72.59      | 2  | 124 | .000 |
| Academic accommodations                  | 127.81     | 2  | 133 | .000 |
| Promotion of independence                | 14.13      | 2  | 109 | .000 |
| Policy development, review, and revision | 28.25      | 2  | 122 | .000 |
| Type of professional                     | 88.04      | 2  | 135 | .000 |
| Acquisition of professional development  | 78.14      | 2  | 135 | .000 |
| Composite                                | 96.20      | 2  | 135 | .000 |

proach significantly higher than a Social approach for the following six components: advocacy (z = -4.865, p = .000), consultation (z = -7.657, p = .000), accommodations (z = -8.506, p = .000), policy (z = -2.748, p = .003), development (z = -8.336, p = .000) and the composite (z = -8.5, p = .000) components of the program standards.

- Participants ranked using a Social approach significantly higher than a universal for the following three components: access (z = -4.528, p = .000), policy (z = -2.8158, p = .002) and professional (z = -8.878, p = .000) components of the program standards.
- Participants ranked using a universal approach significantly higher than asocial for the following five components: consultation (z = -6.518, p =.000), independence (z = -3.721, p = .000), professional (z = -4.1, p =.000), professional development (z = -6.978, p =.000) and composite (z = -2.86, p =.002) components of the program standards; and E) Participants ranked using a universal approach significantly higher than an individual for the independence (z = -2.64, p =.004) component of the program standards.

#### Group differences based on individuals' characteristics

Findings also suggested group differences in a number of areas. This section of the results focuses on significant findings between groups. It includes the participant's gender and years of experience. Findings suggest that significant differences exist between men and women and also depend on years of experience.

#### **Gender Differences**

The results of the Mann-Whitney tests (see Table 6) indicated that male respondents, in comparison to female respondents, ranked significantly higher in individual approach for the advocacy component and the type of professional as well as social approach for accommodations, policy, and composite components. Conversely, findings also suggested that female respondents typically ranked significantly higher in using the universal approach for the access, accommodation components and the type of professional.

#### Years of Experience

The Spearman rank-order correlation coefficient (see Table 7) was used to examine the rankings of the different approaches in relationship to years of experi-

| Male                              |              |      |                                      |              |      |
|-----------------------------------|--------------|------|--------------------------------------|--------------|------|
| Component                         | Highest Rank | р    | Component                            | Highest Rank | р    |
| Advocacy                          | Individual   | .046 | Providing access to campus community | Universal    | .037 |
| Professional                      | Individual   | .040 | Professional                         | Universal    | .010 |
| Providing academic accommodations | Social       | .000 | Providing academic accommodations    | Universal    | .012 |
| Composite                         | Social       | .022 | Composite                            | Universal    | .017 |
| Developing policy                 | Social       | .008 |                                      |              |      |

### Male and Female Comparisons

### Table 7

Findings Comparing Years of Experience

| MORE YEARS OF EXPERIENCE                    |           |      | LESS YEARS OF EXPERIENCE                    |            |      |  |
|---|-----------|------|---|------------|------|--|
| Component Appr                              |           | р    | Component                                   | Approach   | р    |  |
| Advocacy                                    | Universal | .001 | Advocacy                                    | Individual | .002 |  |
| Promotion of access to the campus community | Universal | .004 | Promotion of access to the campus community | Individual | .017 |  |
| Type of professional                        | Universal | .03  | Type of professional                        | Individual | .015 |  |
| Composite                                   | Universal | .013 | Composite                                   | Individual | .01  |  |
| Acting as a consultant                      | Social    | .037 |   |            |      |  |

ence. Findings suggested that participants with more years of experience positively associated with the use of the universal approach for the components of advocacy, access, type of professional, and the composite variable. Similarly, there was a positive association between more years of experience and the use of a social approach for the consultation component. In contrast, participants with less years of experience negatively associated with the use of the individual approach for the components of advocacy, access, type of professional, and the components of advocacy, access, type of professional, and the components of advocacy, access, type of professional, and the composite variable.

#### Discussion

Although the author supports evidence-based standards of practice as a way to improve service delivery (Dukes, 2001), this study identified areas requiring further attention. In response to the hypotheses, the quantitative results pointed toward two key conclusions. First, the individual approach to service provision served as a ubiquitous foundation to the implementation of most of the core AHEAD components as well as the program standards. While certain researchers acknowledge that a need for individualized accommodations will always exist (Block, Loewen, & Kroeger, 2006), the extent to which these accommodations are present in postsecondary education services today misses the opportunity for broader implementation of universal design. Hence, prioritizing the implementation of the program standards from an individual approach serves as the foundation for an environment that singles out and makes the individual responsible for not fitting into an academic setting that lacks universal design.

This analysis also addressed the second hypothesis that disability service providers frame service delivery from a mixed approach. In particular, the study's findings suggested that certain groups and institutions framed program standards using a universal approach significantly more often than did others. Those framers included females, the respondents who had more years of experience, the participants who subscribed to a universal ideology and also institutions that had a higher number of full-time staff in addition to those with the largest number of students.

Also, the study found that female respondents ranked a universal approach higher than their male counterparts. Perhaps this finding can be partially attributed to the larger size of the female sample (82% of the respondents). Previous studies that looked at faculty in higher education showed that female faculty members were more likely to hold positive attitudes towards disability (Aksamit, Morris, & Leuenberger, 1987; Baggett, 1994; Fonosch & Schwab, 1981; Junco & Salter, 2004; Leyser, 1989; Rao, 2002). Additionally, experience also may play a role on the positive attitudes of faculty, as earlier studies have shown more experienced faculty members tended to have more positive attitudes towards disability and accommodations than those with less experience (Fichten, Amsel, Bourdon, & Creti, 1988; Fonosch & Schwab, 1981; Satcher, 1992, Leyser, 1989). And feminist perspectives have offered some interesting nuances to the findings of this study suggesting that, perhaps, female disability service providers possess emotional acumen therefore perhaps offering an explanation for why female respondents in the current study ranked a universal approach higher than did males (Hesse-Biber, 2007; Jagger, 1997).

Despite having doubled the sample size to account for non-responses, the number of respondents did not reach the desired level, which subsequently minimized the study's power (Czaja & Blair, 2005). However, because the study found significant results, such factors may be an indicator of a potential relationship, particularly since lower power typically makes finding significant results more difficult. Another limitation was that AHEAD members in the study represented approximately 28% of accredited institutions of higher education in the United States (AHEAD Annual Report, 2008) and, therefore, results could only be generalized to the targeted sub-group within the whole of higher education. Although the study looked at directors as well as front line personnel, findings did not account for external barriers, such as limited or inadequate resources or administrative opposition that impede or encourage the implementation of the program standards. That omission can potentially bias the findings of this study (Czaja & Blair, 2005). One more limitation is that there was always a potential bias on the part of the individuals that choose to answer versus those who opted not to answer, particularly because the researcher did not know the motivation for individuals choosing not to respond.

As with other research endeavors, this study has created more questions but also has illustrated that practice and theory are currently on different tracks. Future research should focus, among other things, on exploring the tipping point for changing disability service providers' perception of disability as an individual condition or something to be sympathetic about, to a societal problem that places barriers for individuals with disabilities. Other important questions exist: How do researchers and professional leaders ensure knowledge transfer that is usable by practitioners? What are the external barriers to the implementation of social and universal designs? Is there a long-term cost benefit to implementing universal design, not only measured from a dollars and cents perspective, but of an overall improvement in the inclusion and participation of individuals with disability in our society? Which factors currently promote the implementation of these approaches? Since participants, to a small degree, claimed to use other than an individual approach, what are the implications of utilizing a hybrid approach, which combines all three methods? Is there an appropriate balance for mixing these three frames?

For the field of disability studies, it is imperative that more models are developed to ensure that a sound foundation can be established. Disability studies must engage the disability service profession to determine the factors, internal and external, interfering with the implementation of a service model that is consistent with new thinking about disability. It is imperative to recognize that perceptions of disability are shaped by social constructs, yet challenges exist: (1) By valuing independence, one often forgets about the interdependence that is required for our society to function, (2) One may devalue individuals that one considers to be dependent, (3) Thinking about the needs of students prevents the examination of the society which creates barriers, and (4) Hierarchies are thereby created among those considered "able" to help and those considered to be recipients of the help. Critically and honestly analyzing these and other values that individuals are raised to accept instead of challenge may shed light on how an individual approach to service delivery could work in fomenting the oppression current structures exercises on individuals the profession diligently works to include in the postsecondary education system.

For the Association of Higher Education And Disability (AHEAD), this study provides a framework for developing future professional development opportunities. The principal investigator hopes AHEAD will utilize this information to set priorities and to continue to lead the profession into a new paradigm, such as anchoring future revision for the program standards in a "universal approach." In addition, AHEAD may continue to sponsor and increase future professional development opportunities that increase the membership's exposure and access to the scholarship of disability studies and good design practices. AHEAD might also encourage and/or sponsor research that addresses issues relating to the implementation of universal design, which includes cost efficient ways of transferring into a social approach while also collecting data to aid disability providers justify the transition process to academic administrators.

This study shows that despite the fact that many disability service providers speak the language of equality, rights, self-determination, and universal design, their actions are often implemented and guided by dealing with the individual's limitations. The principal investigator recognizes there always will be cases requiring one-onone attention. These cases, however, are not the only barrier to promoting a social or universal approach to service delivery; the real barrier exists because members of society have been and continue to be socialized by media, politics, religion, and the medical profession.

For the disability service profession in higher education, this study presents an opportunity for dialogue and reconsideration of where we have been, where we are, and where we are going. It is important providers move towards reframing disability as a socio-political construct rather than an individual deficit issue. Although challenging, providers and other members in society must first recognize the influences that surround and shape perceptions of disability. Individuals are socialized to value independence and help those labeled 'needy'.

Acknowledging and working to move further away from the individual approach will constitute a leap from practices that continue to discriminate against students with disabilities. Ultimately, this shift should aid in the movement toward a new paradigm that recognizes differences and nurtures them and also works to proactively plan for a diverse student population rather than acting reactively to "need." New paradigms or paradigm shifts are not a simple transition from established practice to innovative and new thinking. The difficulty of the shift lies in that it is very time consuming to evaluate previous assumptions and facts and the change is typically resisted (Kuhn, 1962). Therefore, the challenge before the professional, although attainable, remains a formidable task.

Although AHEAD's program standards are a useful tool for assessment and professional development, the lack of a contextual framework allows for multiple and unequal implementation as demonstrated in this study. Therefore, it is important that AHEAD, as a leading organization, and its members, place careful consideration to the ideologies used to implement the standards. Moving away from a service delivery approach that places great strain on the individual to conform or act like a "normal" person could make for state-of-the-art services in higher education. Moving away from an individual approach will allow all students to participate in an environment which is flexible and responsive, to go in through the same door, and travel the path together.

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# Appendix

Part I. The following section exhibits essential functions or requirements for disability service providers adopted by the Association of Higher Education and Disability (AHEAD). For the following items, please, first answer if the task applies to you presently or at some point in your career. If the specified task is applicable, please rank the statements A through C according to the importance you place on it, either as an approach or philosophy. Place a 1 next to your highest priority, 2 next to the second highest priority, and 3 next to the lowest or non-priority item. All statements, A through C, must be ranked.

- 1. As a disability service provider, have you ever served as an advocate for students with disabilities?
  - Yes No
- 2. When serving as an advocate for issues regarding students with disabilities, I mostly make sure that:
  - a. staff/faculty/administration understand the importance of making campus activities flexible and accessible to the largest number of people possible
  - b. staff/faculty/administration understand the needs of students with disabilities
  - c. staff/faculty/administration understand the impact of physical/programmatic/attitudinal barriers on persons with disabilities
- 3. As a disability service provider, have you ever been responsible for ensuring access to the campus community for students with disabilities?

Yes No

- 4. When providing services that promote access to the campus community I mostly work:
  - a. on providing students with needed technology(ies)
  - b. toward the implementation of universal design in all possible areas
  - c. on ensuring access and usability of available assistive technology(ies)
- 5. As a disability services provider, have you ever acted as a consultant on issues regarding disabilities?

Yes No

- 6. When providing consultation with administrators regarding academic accommodations, compliance with legal responsibilities, as well as instructional, programmatic, physical, and curriculum modifications, I mostly inform them about:
  - a. the role of the environment
  - b. the legal requirements
  - c. proven and new strategies on how to make all relevant areas more accessible and usable by the larger number of people possible

7. As a disability service provider, have you ever been responsible for planning academic accommodations for students with disabilities?

Yes No

- 8. When developing a plan to provide Academic accommodations, I mostly work towards:
  - a. making available reasonable academic accommodations
  - b. having students enjoy a barrier free environment
  - c. minimizing reasonable academic accommodations, by promoting principles of universal design
- 9. As a disability service provider, have you ever been responsible for delivering a service model that promotes students with disabilities' independence?

Yes No

- 10. When implementing a service delivery model that encourages students with disabilities to develop independence, I mostly focus on:
  - a. teaching students how to understand their rights and learn how and when to advocate for changes that include the largest number of people possible
  - b. teaching students how to identify physical barriers and strategies to deal with them
  - c. teaching students how to deal with their disability
- 11. As a disability service provider, have you ever been part on an effort responsible for developing, reviewing, or revising policies?

Yes No

- 12. When developing, reviewing, or revising policies related to service provision, my focus is to ensure:
  - a. that barriers are removed
  - b. that the individual's needs are met
  - c. the promotion of universal design
- 13. The disability service provider should be a full-time professional focused on:
  - a. the elimination of environmental barriers
  - b. understanding individual disabilities and the best strategies to accommodate them
  - c. reframing disability and making system change
- 14. The best professional development activities are:
  - a. those focused on creating truly inclusive environments
  - b. those focused on eliminating environmental barriers
  - c. those focused on understanding all aspects of disability/reasonable accommodations

# **Professional Perspective**

#### Katheryne Staeger-Wilson Director, Disability Services Missouri State University

Guzman explores historical developments within our profession, legal mandates, and three views of disability: individual/medical, social, and universal. He then significantly exposes the disability service industry and provides ideas on how we might begin a paradigm shift in our service delivery.

He illustrates, through his research, how some disability service professionals understand and identify with progressive models of disability, such as the social and universal models. However, most of us are not progressive in our practices and continue to work in ways that are guided by the individual/medical model. We still look at individual deficits and attempt to normalize students with disabilities through retrofits and accommodations. His work prompted me to ask: Why does our work not reflect progressive approaches? How are we creating and maintaining barriers on our campuses?

We need to embrace disability studies and reframe our own perceptions of disability. Only then can we accurately evaluate our work and biases, and encourage others to do the same. We can redefine the disability service industry by considering the following questions:

- Have we taken the time to explore and understand the field of disability studies and to examine the role the disability service industry plays in the marginalization of disabled people?
- What model of disability does our language reflect? What messages are we sending to students, faculty, and staff?
- What model of disability is reflected in our trainings? Do we promote disability assimilation and promote stereotypes, or do we focus on barriers that society creates? Do we educate so that we as a community proactively design equitable and inclusive learning environments?
- When looking at equal access issues, do we focus on the individual's deficits and the minimum legal requirements, or do we question our college and university environmental designs (curricular, physical, social, information, policy)? Do we value and proactively plan for a diverse student population?
- Are we resisting the change that is needed to move

our profession forward, and to improve the perception of disability? If we are resisting change, what is the cause of that resistance?

- How can we share what we learn about ourselves through the exploration of disability studies and progressive disability models?
- How can we become change agents on our campus and in our profession?
- We must work to create a stronger partnership between studies and services so that we understand how professionals help maintain a deficit frame of disability and why we, and our professions, are such critical components in achieving social justice for disabled people.

# A Disability Studies Framework for Policy Activism in Postsecondary Education

### Susan L. Gabel National-Louis University

#### Abstract

This article uses disability studies and the social model of disability as theoretical foundations for policy activism in postsecondary education. The social model is discussed and a model for policy activism is described. A case study of how disability studies and policy activism can be applied is provided utilizing the "3C Project to Provide Students with Disabilities a Quality Higher Education," a federally-funded development grant."

#### A Disability Studies Framework For Policy Activism in Postsecondary Education

Disability studies (DS) is an interdisciplinary area of study that situates disability at the center of the humanities, sciences, social sciences, and applied fields of study. Disability studies "challenges the view of disability as an individual deficit or defect that can be remediated solely through...intervention by 'experts' and other service providers" (Society for Disability Studies [SDS], 2004). The applied field of Disability Studies in Education (DSE) holds to tenets consistent with those identified by the Society for Disability Studies (above). More specifically, DSE aims to

- contextualize disability within political and social spheres;
- privilege the interests, agendas, and voices of people labeled with disability;
- disabled people;
- promote social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people; and
- assume competence and reject deficit models of disability (Connor, Gabel, Gallagher, & Morton, 2008, p. 448).

While specific guidelines or tenets have been identified, "neither Disability Studies nor Disability Studies in Education represents a unitary perspective" (Taylor, 2006, p. xiii). However, scholars of disability studies agree that disability is a social construct (Connor, et al., 2008, p. 447), accordingly, "disability is not a 'thing' or condition people have, but instead [it is] a social negation serving powerful ideological commitments and political aims" (ibid.). The proposition that disability is socially constructed by the enactment of ideology and political aims is often referred to as the "social model of disability."

#### Social Model of Disability

Multiple versions of the social model exist in the literature. The oldest, a neo-Marxist version, is sometimes referred to as the "strong social model" (Shakespeare & Watson, 2001). It differentiates between impairment or functional limitations experienced by an individual, and disability or the marginalization and even oppression of people with impairments as a group. This strong social model critiques the structural and institutional barriers that prevent people with impairments from full participation in all aspects of society (Priestly, 1998). This places disability as located "squarely within society" rather than in individuals. Furthermore, as to whether impairment or functional limitation of some kind is addressed in this model:

it is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization (Oliver, 1996, p. 32). Oliver was influenced by the Disabled People's Movement in the United Kingdom and the publication of the *Fundamental Principles of Disability* by the Union of the Physically Impaired Against Segregation ([UPIAS], 1975).

Oliver is speaking to what Priestly (1998) has described as the "material product of socio-economic relations developing within a specific historical context" (p. 78). Priestly positions this as a realist account where the "units of analysis are disabling barriers and material relations of power" (ibid.). The strong social model's materialism sometimes is described as a reductionist account that ignores the interactions between individuals and society and, in fact, disability studies scholars have criticized it for this and other reasons (Gabel & Peters, 2004; Shakespeare & Watson, 2001). However, the strong social model is a useful framework for strategic action in policy because it clearly focuses attention on the institutional structures that disable people by putting up barriers to full inclusion.

Priestly (1998) describes another form of the social model of disability as the social constructionist model in which disability is the "product of specific cultural conditions," or the "product of societal development within a specific cultural context" (p. 81) where "the units of analysis are cultural values and representation" (p. 78). In other words, culture at-large constructs disability through what is held to be true about normalcy and how truth is represented in cultural symbols, practices, and rituals. Cultural symbols that affect disabled people include disability stereotypes and visual representations. For example, the stereotype of disabled people as weak and incapable can lead to the view of disabled students as "watering down the college curriculum." Cultural practices include policies, procedures, and traditions that lead to segregation and social isolation. For example, technology policies inattentive to access issues thereby excluding some students from information systems, procedures for obtaining accommodations that require students to selfidentify and that may increase the stigma associated with impairment, or the tradition of postsecondary education as a meritocracy that historically has excluded disabled people from entry. Cultural rituals can also disable people. For example, rituals of standardized testing that serve as mechanisms for gate-keeping into postsecondary programs, and rituals of testing and assessment that may label disabled students who have been admitted to a program as "not meeting program standards."

#### Applying DS framework to postsecondary policy work

The two versions of the social model of disability discussed in the previous section-the material with an emphasis on socio-economic factors and the cultural with an emphasis on symbolism, representation, and value-are useful in postsecondary policy work that aims to address the institutional structures that can disable people. Material structures can be understood as those that are designed to provide resources and/or support to students, for example, scholarships, loans, tutoring, library books and articles, and of course accessible built environments. Cultural structures, the values, symbols, and representations infused throughout the postsecondary milieu, are those underlying frameworks and assumptions that influence behavior, discourse, policy, and practice. Examples of cultural structures include institutional marketing materials (e.g., who is depicted as a student at the institution?), mission statements (e.g., are access or diversity included and if so, how are they understood and enacted?), and admission and retention policies (e.g., what are the gatekeeping devices and who do those devices exclude?).

#### **Examples from the 3C Project**

Examples from a federally funded development grant-the 3C Project-can be useful in understanding the applications of disability studies to postsecondary policy activism, or policy work that has social justice aims. As an introduction, I briefly describe the 3C Project (funded by US Department of Education Office of Postsecondary Education grant #P333A080036), whose purpose is to provide a quality higher education to students with disabilities. The 3C Project at National-Louis University (NLU) in Chicago, Illinois, aims to create a model for institution-wide change in access and inclusion for students with disabilities. The three Cs represent the project's policy foci. Context refers to three contexts of teaching and learning: contexts internal and external to the university, contexts that are both face-to-face and virtual, and contexts that are local and national. Content refers to three types of content knowledge needed to provide students with a quality education: technological content, practical content, and theoretical content. Culture refers to a culture of inclusion for which all community members are responsible. The culture of inclusion entails creating visibility, accessibility, and possibility. In sum, the 3C Project provides support and professional development for administration, faculty,

and staff to improve their ability to: (1) provide and facilitate contexts that support learning, (2) make content accessible to all learners, and (3) create a culture of inclusion. While it is necessary to involve students in creating a culture of inclusion, the social model of disability emphasizes the responsibility of society at large for dismantling barriers and creating inclusivity, so the 3C Project focuses on the responsibilities of university employees for creating an inclusive community.

#### **Policy Model and Process Part I: Policy Streams**

Part one of the model of policy activism (Gabel, 2008) is borrowed from Weiss' (1990) scholarship on policy advocacy, a concept of policy making structured by argumentation and political timing in what John Kingdon (2003) calls the "policy primeval soup" (p. 116), where ideas float around disconnected from problems or solutions. It is in this milieu that ideas become prominent and then fade," "soften up," "confront one another and combine with one another in various ways" (Kingdon, 2003, pp. 116-117). The idea selection process, which leads to the development of new policy, depends on what Kingdon (2003) refers to as an open policy window, or that moment at which problems and potential solutions (or alternatives) convene with the political ripeness that creates opportunities for the policy worker to intervene, offer solutions, and influence change.

At the postsecondary level, the policy soup can start bubbling for a variety of reasons. At NLU, the policy soup started bubbling with the 2005 recommendation from education doctoral students (Becker, Kleish, & Stern, 2005) that the university should adopt a universal design (UD) or universal design for learning (UDL) model of supporting students with disabilities. From 2005-2008, Kingdon's notion of softening up of ideas as well as the confrontation and recombination of ideas was observed: (1) Education college faculty produced a White Paper (Gabel, German, & Wu, 2006) arguing for incorporating UDL into the college strategic plan, (2) online conversations (debates) among college faculty ensued, and (3) the college strategic planning committee included "access" in one of its goals while rejecting wording specific to UDL. Although the decision to avoid specific reference to UDL was disappointing to faculty supportive of the idea, the softening up process had begun and led to the submission of the OPE grant proposal in 2008.

Simultaneously, the University Diversity and Inclu-

sion Council began debating the meaning of diversity and eventually included "ability diversity" in its mission statement in 2008. This was the first time the university had defined diversity to include dis/ability.

Kingdon's (2003) is a policy model in which the primeval soup gives rise to three policy streams that run simultaneously and in parallel: (1) problems, (2) solutions or alternatives, and (3) politics (Figure 1). The problems stream is composed of those individuals or groups working toward identifying and defining problems or refining problems that have been identified by others. The solutions or alternatives stream is where solutions are actively created and made ready to combine with problems when the time is right, when a window opens. The third stream, the *political*, is composed of policy elites-for Kingdon, legislators and their aides, but in this case, higher level administrators and the Faculty Senate, which has some authority in policies affecting faculty and student learning. The streams represent a fluid and somewhat unpredictable model. When all three streams converge-the political atmosphere is just right, problems are clearly defined, and solutions are available and acceptable-consensus may emerge and policy may be shaped.

Problem stream. As discussed earlier, a problem had been identified in 2005 by doctoral students and subsequently by some faculty as the ineffectiveness or lack of use of campus disability services and the lack of faculty awareness of a UDL model. However, over the years, the problem came to be redefined by those involved in this initiative as multi-pronged and more complex, including, for example: (1) contextual barriers, such as inaccessibility and exclusion resulting from the well-intentioned but insufficient compliance model of service delivery at the institutional level (Cory, Taylor, Walker, & White, 2003), including insufficient resources to sustain the model (e.g., assistive technology); (2) content barriers, such as the lack of institutional knowledge of the percentage of disabled students it is serving and the subsequent inability to assess program effectiveness with disabled students; and (3) cultural barriers constituted through the construction of disabled people as invisible in the university community, leading to stigma, exclusion, isolation, and the inability of the university to be accountable for its work with disabled students.

Examples of the above barrier categories can demonstrate the depth and typicality of the problems. Within the compliance model (problem 1 above) the focus is on the "letter of the law" and regulatory policies but while compliance might meet the "letter of the law," it can be unsatisfactory on many levels (Burgstahler & Cory, 2008; Cory et al., 2003). The compliance model requires students to self-identify to receive disability accommodations. Many students avoid self-identifying for fear of stigma (Izzo, Murray, & Novak, 2008). Other students do not realize they have conditions that interfere with learning. At NLU, this is often the case with older students who have developed age-related conditions. Compliance models require students to qualify as disabled. Qualification often requires medical or psychological evaluations that can be expensive and time-consuming as well as disturbing or discouraging. Many students cannot afford these evaluations or avoid them for other reasons. Finally, compliance models do not account for the fact that many students struggle academically for reasons other than disability (e.g., cultural or linguistic differences) and only address the need for accommodation on a case by case basis without the view to an overall plan for inclusion (Izzo, et al., 2008). Consistent with these criticisms, prior to 2009, less than 1% of NLU's students had self-identified as disabled using the university's compliance procedures.

However, by 2009, 14% of NLU's students identified as disabled via the ACCESS survey available from AHEAD (Vogel, 2008) and a survey the grant project entitled the "3C Student Census," closing the gap on a content barrier (problem 2 above) at the university. These surveys collected important data, including the disability categories identified by students, college attendance, campus attendance (NLU has 5 Chicago area campuses), and other useful information.

As an open-access university, NLU's history and student body lends itself to a learner-centered approach. However, as indicated in problem 3 above, prior to 2005, it was unclear whether faculty were aware of the historical increase in the number of students with disabilities attending institutions of postsecondary education. Faculty members from a variety of departments and disciplines often claim to have never had a student with a disability in the classroom, suggesting that faculty expected to be able to *see* whether or not disabled students were in their classes. The assumption that disability is visible is a content barrier (problem 2). Disabled people also have been invisible in the cultural artifacts of NLU marketing materials and websites, for example.

*Solution stream.* Years ago, the small group of doctoral students concerned about these issues thought the solution would be to substitute UDL for the compli-

ance model. This was one of the aims of the 3C Project, however it is clear at this time that the solutions are much more complex than merely implementing a UDL model. One must remember that the process of institutionally defining problems and solutions is fluid and somewhat unpredictable. Faculty, staff, and student awareness of ableism (Hehir, 2002) and disability stereotypes (Davis & Watson, 2002) is needed, as are a recognition of the way barriers disable people, knowledge and skill in inclusive teaching through UDL or any framework designed for access that avoids retrofitting whenever possible, and the capacity to respond effectively to student needs for accommodation. The stigma of disability needs to be minimized so that disabled members of the learning community feel more comfortable openly identifying and sharing their experiences as opposed to answering questions on an anonymous survey. This can be assisted by creating visibility in the cultural artifacts produced by the university: websites, marketing materials, and the curriculum (e.g., history of the disability rights movement in history classes, contribution of disabled people to science, disability art in fine arts classes, etc.). Kingdon's (2003) model suggests that these solutions need to be well considered and ready for an open policy window. However, at this university as at other large institutions, policy windows are influenced by the politics that percolate in the political stream.

*Political stream.* At the postsecondary level, the political stream includes a variety of local actors, including faculty leaders (department heads and senior faculty), college administrators (Deans), university administrators (Provost, Vice Presidents, President), and the Board of Trustees who are the ultimate policy elites of the university.

The political stream operates at international, national, state, and local levels. The importance and value of higher education for a broad spectrum of the world's population has been on the international agenda for over a decade. *The World Declaration on Higher Education* (United Nations Educational, Scientific and Cultural Organization [UNESCO], 1998) argues that "education is a fundamental pillar of human rights, democracy, sustainable development and peace" and that "the solution of [sic] the problems faced on the eve of the twenty-first century will be determined ... by the role that is assigned to education in general and to higher education addresses equity of access, stating that "no discrimination can be accepted in granting

access to higher education" and that "access to higher education for members of some special target groups," including disabled people according to the Declaration, "must be actively facilitated" with "special material help and educational solutions" that "can help overcome the obstacles that these groups face, both in accessing and in continuing higher education."

At the state level, the Illinois Board of Higher Education's ([IBHE], 2007) blueprint directing state policies and resources to higher education very specifically speaks to the issues raised in this case. The IBHE's (2007) *Public Agenda for Illinois Higher Education* found

a tale of *two states of Illinois*. One is prosperous; the other is struggling. One is well educated; the other lags in educational attainment. One is economically vibrant; the other is economically stagnant. Between these two states is a prosperity gap that is wide and growing and the direct result of disparities in educational attainment by race, ethnicity, income, and region. (p. 3, emphasis in original)

Later, the document notes that "the growth of nontraditional students and students of racial and ethnic diversity *and those with disabilities* is altering the face of postsecondary education" and that "large disparities exist in educational attainment by race/ethnicity, income, *disability*, and region" (¶4, emphases added). The blueprint outlines a series of goals with recommendations, including goal three, "Increase the number of quality postsecondary credentials to meet the demands of the economy and an increasingly global society" (IBHE, 2007, p. 5).

Goal one of the blueprint, "increase educational attainment to match best-performing U.S. states and world countries" (IBHE, 2007, p. 13), includes a strategy specifically directed at "improve[d] access for students with disabilities" and a set of action steps, the first of which is reminiscent of the HEOA:

- Improve student success in college through improved accommodation of students with disabilities through full access to the Internet and online information for students with disabilities, regardless of disability; the use of assistive technology; providing students information about careers and employment, internships, and work study, along with information about the importance of self-advocacy and how to do it.
- 2. Collaborate with P-20 institutions to improve transition of students with disabilities from P-12

to college, and from college to employment, including documenting employment status of students and graduates with disabilities.

3. Implement Perkins Programs of Study that specifically target individuals with disabilities (p. 13).

The IBHE Task Force (2007) documents that "only 25% of the parents of students with disabilities indicate that their child received career development training before or during postsecondary education" (p. 20), necessitating a recommendation to "improve transitions all along the educational pipeline, including from adult education to postsecondary education, from remedial classes to credit-bearing coursework, and from associate to baccalaureate degree levels" (p. 5).

Finally, the Public Agenda recommends that "a comprehensive P-20 student information system is vital for sound policymaking and accountability" (IBHE, 2007, p. 10). The IBHE's observation that "data on students in Illinois are fragmented and inadequate to answer key policy questions regarding student demographics" (ibid.) has been the observation of the staff of the 3C Project, as well. This is in part the result of the national trend in using a compliance model of accommodation, under which students are only served if they self-identify. The model does not provide the necessary and comprehensive information to make what IBHE refers to as "sound" policy decisions. For example, the compliance model does not require a "comprehensive student information system" that tracks disabled students from secondary to postsecondary programs, particularly for those students who fall outside the purview of the Individuals with Disabilities Educational Improvement Act (IDEA). Neither does the compliance model require postsecondary institutions to compare course or program completion rates of disabled students to that of non-disabled students (e.g., a requirement in the OPE grant funding the 3C Project).

In this section I have shown how disability can be contextualized "within political and social spheres" when thinking about and engaging in policy. This contextualization is consistent with the first tenet of DSE as introduced in the beginning of this article (Connor, et al., 2008). In the next section another tenet of DSE is integrated: privileging the interests of disabled people, promoting social justice, and assuming competence.

#### Policy Model and Process Part II: Discourse Coalitions

Weiss (1990) has pointed to argumentation as an important factor in policy development, yet argumentation for UDL had not been fully effective prior to the OPE award funding the 3C Project. For example, a White Paper did not achieve its ultimate purpose of persuading faculty to include UDL in the strategic plan. Therefore, the 3C Project was structured around a policy process that Hajer and Wagenaar (2003) have framed as "discourse coalitions." Other researchers also propose similar discursive processes: for example, Stone (2002) emphasizes a more dialogical process of deliberation, Fischer (2003) suggests the importance of "public enlightenment" through deliberation (p. 12), and Roer-Strier (2002) describes "raising awareness" and "building partnerships" (p. 914). To be successful in building discourse coalitions, policy activism must be persuasive to a wide range of stakeholders, particularly those who are likely supporters, by giving them what Weiss calls "talking points" and Fischer refers to as "story lines." This increases the range of the policy discussion to include those who share or might share the policy goals, but who would be unlikely to participate in the policy discussion without such talking points.

Prior to and during the early OPE funding period at NLU, several talking points or story lines were developed. One story line points out the problems associated with compliance models as they might affect faculty and the university as discussed above. One story line has been framed this way: prior to the 3C Census, we (NLU) suspected that about 10% of our students are probably disabled, per the US Department of Education (2006), but we were not aware of who they are and could not assess their course or program completion rates, therefore we need a strategy for building institutional capacity and understanding of such issues. Another story line goes this way: the 3C Project is going to increase demand on the disabled student services office and we will not have the capacity to meet this demand unless we adopt a UDL model that serves the majority of our students. The project also created what the marketing department referred to as a "tag line"-"creating a culture of inclusion"-that encapsulates the central purpose of the project and serves as another story line or talking point. When Project staff present to stakeholder groups, they inevitably use the phrase, "everyone is responsible for creating a culture of inclusion." Another story line addresses the problems of "retrofitting" associated with differentiated instruction and compliance models and points out the benefits of UDL in avoiding the need to retrofit courses (Izzo, et al., 2008). For example, getting an accommodation letter after faculty have already finished the syllabus without regard to UDL can create anxiety and stress and minimize student access to learning opportunities. To date, anecdotal information suggests that these have helped project staff to talk differently about access and inclusion, although empirical data have not been collected to support this. In fact, Fischer (2003) notes that empirical evidence may be difficult to uncover since discourse coalition members "share a particular way of thinking about and discussing ... issues" that cannot necessarily be "nailed down empirically" (p. 13).

According to Hajer (1993), competing story lines emerge when different discourse coalitions talk about an issue and alternatively, discourse coalitions form when actors and practices merge with a story line. Two distinct story lines are depicted (Figure 1) as permeable circles in the policy streams. Think of them as (1) a story line about the problem of the resources a UDL model may help to solve, and (2) a story line about a solution, or the benefits to faculty and students when retrofitting is avoided by using UDL. The actors and practices that conform to these story lines can be imagined as entering the broader policy stream, combining and recombining until they merge (Figure 1) and, according to Kingdon's (2003) metaphor, remain ready for when the political climate is right and a window of opportunity opens. For example, a window might open when the political climate is such that decision-making bodies at the university have agreed on the problem and solution(s) and move to enact policy marrying problem to solution (i.e., the open window).

The above examples speak to the DSE tenet of promoting social justice. Part II of the policy activism model also is where the tenets of privileging the interests of disabled people and assuming competence can be enacted. From a disability studies perspective, discourse coalitions should solicit and include disabled people when the coalitions are formed around disability issues. In fact, DSE tenets would hold that disabled people's interests and agendas should guide coalition efforts at defining problems, identifying solutions, and influencing politics. By assuming the competence of disabled people, a DSE framework would also assume that disabled people are the best ones to define their goals, vision, and hopes for their own postsecondary education.

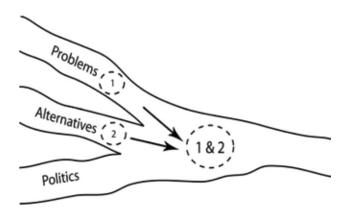


Figure 1. Model for Policy Activism

#### Conclusion

Two versions of the social model of disabilitymaterial and cultural-are represented in this article and in the 3C Project. Materially, the project aims to dismantle the barriers to full inclusion in postsecondary education at NLU, while the model for policy activism provides a framework that understands policy work as fluid, dynamic, political, and dependent on the deliberations and debates of discourse coalitions. Culturally, the project aims to instill the belief that it is everyone's responsibility to create a culture of inclusion and that this entails making disability visible in a variety of ways: (1) in visual representations such as marketing materials; (2) in institutional strategies for knowing how many disabled students are attending, which programs they are in, whether they are being retained, and whether or not they view their education at NLU to be fulfilling; (3) and in understanding the types of impairments NLU students report and how the university might better meet their needs.

In my reporting of the criticisms of a compliance model of disability support services, I have implied that a disability studies perspective might minimize the compliance model's value and uses. Indeed, while I understand it as a minimum requirement under the law and therefore necessary, I do not view it as sufficient for creating an accessible university inclusive of disabled people given the tenet of DSE that specifies "inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people" (Connor, et al., 2009, p. 448). "Full and meaningful access" cannot be achieved if only those individuals who self-identify and prove eligibility as disabled are provided with accommodations. Consequently, a disability studies framework for postsecondary education policy would have to go "beyond compliance" (Cory, et al., 2003), using policy activism to move forward "full and meaningful access" in all ways necessary for all students.

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### Professional Perspective Amanda Kraus Director of Veterans Reintegration and Education Project University of Arizona

In her article, Susan Gabel, discusses the 3C Project, a federally funded postsecondary education grant that seeks to provide a quality higher education to disabled students. More than her immediate discussion of the 3C Project, Dr. Gabel looks critically at the compliance model of disability support services, challenging commonly held notions of access, inclusion, and equity in an educational context. She puts forward that not until our practice is truly informed by disability studies and the social model of disability, will we see an educational culture of equity for all students. She astutely asserts that it is "everyone's responsibility to create a culture of inclusion"...not only that of service providers or disabled students.

Dr. Gabel provides two definitions of the social model of disability that are both important to the implementation of the 3C Project and relevant to our understanding of disability. The Strong Social Model critiques structural and institutional barriers that deny disabled people access to resources and participation in society (Shakespeare & Watson, 2001). Another conceptualization is the Social Constructionist Model that asserts that disability is defined and understood within a cultural context of symbols, rituals, and messaging (Priestly, 1998). Understanding the subtleties between these versions helps provide a more complete picture of the disability experience as related to access and oppression critical to our profession. The 3C project is informed by these models and addresses different dimensions of the educational experience, promoting systemic change that will advance our educational culture to one of inclusion. Dr. Gabel boldly asks us to look outside our immediate scope, move past our individual responsibility to facilitate accommodations, and work toward changing our culture...both that of our profession and of higher education.

### **PRACTICE BRIEF**

# Walking the Walk: Social Model and Universal Design in the Disabilities Office

### Melanie Thornton Sharon Downs University of Arkansas at Little Rock

#### Abstract

Making the shift from the medical model of disability to the social model requires postsecondary disabilities offices to carefully examine and revise policies and procedures to reflect this paradigm shift, which gives them the credibility to work toward such change on the campus level. The process followed by one university is covered in-depth, as well as outcomes and implications.

An increasing number of disability professionals in higher education settings are promoting the concept of universal design (McGuire & Scott, 2006; Burgstahler & Cory, 2008; Scott, Loewen, Funckes, & Kroeger, 2003). The primary focus of these efforts has been on the instructional environment. A review of projects recently receiving federal funding to improve the quality of education for students with disabilities reflects this same trend as the majority of these project provide resources and professional development to faculty, but do not address the disability service environment (U.S. Department of Education, 2008). Block, Loewen, and Kroeger (2006) suggest that in order to "implement a change in philosophy on campus, staff in Disability Services offices must explore and identify changes they can make in their offices and departments in order to model the paradigm shift to other institutional staff." Guzman (2008) challenges disability professionals to incorporate the disability studies perspective into the service model. Though this challenge has been issued to disability professionals, and several professionals are cited as restructuring the service environment, the professional literature is lacking in terms of models of implementation and in terms of the impact that these changes have on the campus environment.

#### Problem

Historically, society has viewed disability in a negative light. In this view, the disability is a "problem" that exists within the person and the goal is to "fix" that person. This medical model view of disability has been central to our culture for so long that it should be no surprise that many people have a negative connotation of even the word "disability." Project PACE at the University of Arkansas at Little Rock (UALR), under what was then known as Disability Support Services (DSS), was the leader in moving the campus toward reframing disability and embracing the social model, which posits that disability is an aspect of one's diversity, and therefore is not something to be viewed negatively (Gill, 1994). Faculty development was conducted in an effort to educate about universal design, and one-onone technical assistance was provided to help faculty and staff make this shift. It became apparent, however, that DSS was not modeling the behavior it was trying to teach, because DSS policies and practices clearly reflected the medical model of disability. In order for efforts to promote social model and universal design to be credible, the DSS staff needed to take a step back, look inward and make changes that reflected these core values. The staff recognized the need to explore messages conveyed through the name of the office, mission statement, syllabus statement, letters to professors, documentation and guidelines, and all policies and procedures, and to modify those to be in line with the desired paradigm shift.

#### **Students and Location Information**

The UALR is a metropolitan commuter university centrally located in the state. Only a few miles from the UALR campus is Lion's World Services for the Blind, the Arkansas School for the Deaf, and Arkansas School for the Blind. UALR has a large percentage of nontraditional students, with the average student age being 28 years. UALR has enjoyed a favorable reputation nationally for the work done by the disabilities office, largely due to innovative grant projects over the last couple of decades. In addition, UALR has a dynamic online master's degree program in rehabilitation counseling. For all of those reasons, UALR attracts many disabled students from the area and all over the country. Over 35% of students in the rehabilitation counseling program alone have disabilities (G.M. Szirony, personal communication, March 12, 2009). The University is known nationally for its innovative services for deaf and hard of hearing students, including an exemplary speech-to-text program, for creating disability-related professional development videos and handbooks that are utilized around the world, and for the support from administration in disability-related matters.

#### Strategy

In an effort to identify strategies for sustaining the changes being made on the UALR campus through a grant-funded program called Project PACE, the Director participated in an online course offered by AHEAD in the spring of 2006 entitled "Acknowledging and Transforming Disabling Environments." As a direct result of this institute, the PACE Director met with the Director of the DSS office at that time, Susan Queller, to discuss plans for modifying language and practices of the DSS office. A planning retreat of the complete staff was held and this was included as one of the priorities for the office's five-year plan. Preliminary discussion occurred among the staff regarding the rationale and purpose for this objective.

The DSS management team met to establish priorities for change. As recommended in Block, Loewen, and Kroeger (2006), the management team did a preliminary review of the documents and web presence of the office and analyzed them in terms of the messages they were sending, considering whether they reflected social model or medical model approaches to disability. A cursory review clearly identified a problem with consistency of message and resulted in the establishment of some initial priorities.

A strategic planning approach to making changes was implemented to address the concerns that were identified by the management team. This was a questiondriven process which posed the following questions: Who are we? Where are we now? Where are we going? How will we get there? How will we know when we are there? Through this process, the management team identified several layers to address in the process of becoming more aligned with the vision of full inclusion of people with disabilities for the campus community-focusing solely on those areas under the purview of the disability service office. The identified areas of focus might be divided into four over-arching areas-language, policy, process, and practice-though it is acknowledged that some overlap exists between these broad categories. The management team chose language as the first priority and this area is thus the primary focus of this practice brief.

Second to changing the name of the office to Disability Resource Center (see Table 1), the mission statement was identified as the most critical item to address. The entire DSS staff engaged in a discussion of the importance of changing the language in the mission statement and worked collaboratively to make changes to the language that reflected current thinking about disability. The former mission statement was written several years prior and the language clearly reflected medical model thinking. Words like "assisting." "insure," "support services," "special needs," and "allow" emphasize the disability professional as being the expert who is helping the student achieve access and success. The focus is on the student rather than the environment.

*Former mission statement*: The mission of DSS is to eliminate physical and academic barriers and to fulfill the Division of Educational and Student Services concept of assisting students in achieving their educational, career, and personal goals through the full range of institutional and community resources. In addition, the office was established to insure that students with special needs receive support services and accommodations to allow them equal access to all UALR programs, and that they have the opTable 1

Office Name

| Old                   | <b>Disability Support Services</b>   |  |
|-----------------------|--|--|
| Problems              | • The terms "support" and "services" reflect a medical model perspective. They imply that students with disabilities need "support" and keep the focus on the student as the problem rather than placing the focus on environmental barriers.  |  |
| New                   | <b>Disability Resource Center</b>  |  |
| Reasons for<br>change | <ul> <li>We want to create an image that is consistent with the other shifts we have made over the years. We are a resource to students and to the campus community and provide services to both.</li> <li>Often, in fact, our role is to assist the campus community in creating more usable and inclusive environments. When this is accomplished, access for students with disabilities is seamless.</li> <li>The name "Disability Resource Center" indicates that we are a resource to students as well as other members of the campus community. Through the years we have taken on the role of providing resources and technical assistance even beyond the campus community, in both a routine and very regular way when our colleagues from other institutions call us for assistance and advice, and through programs such as PACE and PEPNet-South/Arkansas SOTAC.</li> <li>Some offices are choosing names that place the focus more directly on the environment—such as Center for Educational Access or similar names. We acknowledge that these names do indeed reflect social model in that they place the responsibility for access less on the student and more on the environment. However, some proponents of name changes that remove the term "disability" argue that students steer away from their office because of that term. This is a reflection of the problems of our society and the lack of acceptance of diversity. We want to change the way people think about disability rather than shrink away from the reactions that people have to that term. We hope that through our work, our campus community will begin to see the power that goes along with that term and will embrace the rich history of the disability rights movement. We hope that they will come to see disability rather sources that remove the term and will embrace the rich history of the disability rather source of diversity that is integral to our society and to our campus community.</li> </ul> |  |

portunity to realize their potential.

The new mission statement was crafted based on the language from several other sources. It includes language from the mission statement of UALR's Educational and Student Services Division, the AHEAD UD Initiative model mission statement, and University of Arizona's mission statement. It is more consistent with new thinking about disability and with the current focus of the office. It emphasizes the collaborative role of the staff and changing the environment rather than simply responding to each student's access request.

*New mission statement*. Providing access to a diverse student population is embedded in the philosophy of the University of Arkansas at Little Rock. We recognize disability as an aspect of diversity that is integral to society and to the campus community. To this end, the Disability Resource Center collaborates with students, faculty, staff, and community members to create usable, equitable, inclusive and sustainable learning environments. We promote and facilitate awareness and access through training, partnerships, innovative programs and accommodations.

The focus of this statement is on collaboration with students rather than support or service to students. Words like "usable," "equitable," "inclusive," and "sustainable" integrate the concept of universal design into the office mission.

The office staff continued with this process, reviewing and modifying the office name, the office tag line, the office structure, job descriptions, position titles, documentation guidelines, letters to professors, and syllabus statement. A few examples of these changes can be viewed in Tables 1, 2 and 3. For each change, the staff documented the old version, the problems with that version, the new version, and the rationale for the change. To date, the DRC has updated almost every publication and the majority of language on the web site, as well as some policies and procedures, to reflect this paradigm shift. The student handbook has been completely revised, and the Disability Resource Center staff has dramatically changed the faculty handbook as well.

#### **Observed Outcomes**

The process of collaborating as a team to make the changes was extremely beneficial as it highlighted the different perspectives individual staff members brought to the table with regard to disability and the role of the disability office. The process increased awareness of the need for ongoing dialogue among all of the staff as they work to create a paradigm shift both within the office culture and in the campus as a whole.

Several members of the staff in the Disability Resource Center have reported increased job satisfaction as a result of these changes. The shift to more proactive roles has been especially meaningful for many of the staff. Under the old system of focusing solely on accommodations, staff often felt they were 'bailing water,' and never truly making a difference. The new focus on the environment and making systemic, proactive change

#### Table 2

Office Name

| Old                | The Education You Want, The Services You Need   |  |
|--------------------|---|--|
| Problems           | <ul> <li>Focus is on the student's needs, not on the need for changes in the environment.</li> <li>Communicates that the student needs professional services to get an education</li> </ul> |  |
| New                | Creative Solutions. Together.   |  |
| Reasons for change | • Can include either environmental changes or accommodations, but has a more positive feel and emphasizes collaboration.  |  |

### Table 3

### Syllabus Statement

| Old                   | Disability Support Services: It is the policy of UALR to accommodate students with disabilities, pursuant to federal law and state law. Any student with a disability who needs accommodation, for example in arrangements for seating, examinations, note-taking, should inform the instructor at the beginning of the course. It is also the policy and practice of UALR to make web-based information accessible to students with disabilities. If you, as a student with a disability, have difficulty accessing any part of the online course materials for this class, please notify the instructor immediately. The chair of the department offering this course is also available to assist with accommodations. Students with disabilities are encouraged to contact Disability Resource Center, telephone 501-569-3143 (v/tty), and on the Web at (former website). |  |
|-----------------------|---|--|
| Problems              | <ul> <li>Language emphasizes legal requirements and the student as the locus of the problem.</li> <li>When legal mandates are emphasized, it creates a culture that asks, "What do we have to do? What is required? What is the minimal response?"</li> <li>The statement is labeled "Disability Support Services" which sends the message that access is directly tied to that office, rather than being available to all students with disabilities.</li> </ul>   |  |
| New                   | Students with disabilities: It is the policy and practice of the University of Arkansas at Little Rock to create inclusive learning environments. If there are aspects of the instruction or design of this course that result in barriers to your inclusion or to accurate assessment of achievement—such as time-limited exams, inaccessible web content, or the use of non-captioned videos—please notify the instructor as soon as possible. Students are also welcome to contact the Disability Resource Center, telephone 501-569-3143 (v/tty). For more information, visit the DRC website at www.ualr.edu/disability.   |  |
| Reasons<br>for change | <ul> <li>The language places the problem with access in the environment and the responsibility with the designer of the course.</li> <li>It is addressed to "students with disabilities" rather being tagged with the office name. Some barriers can easily be removed as a result of collaboration between the student and the professor without further intervention. This statement leaves room for that process to occur.</li> </ul>  |  |

has proven to be quite appealing and energizing for the DRC.

Disabled students have reported being pleased with the shift in focus from the individual to the environment. The concept of the social model has helped some recently-disabled students to reframe how they view themselves and their disabilities. Some students have reported feeling empowered by the teamwork approach to making environments at UALR more usable.

DRC personnel continue to make modifications to policies and procedures recognizing that this process is ongoing. Now that significant changes have been made in the DRC, efforts have been renewed to influence faculty and staff to embrace these concepts. Efforts to date have focused on presenting to the Chancellor's Leadership Group, the Dean's Council, Educational and Student Services, Academy for Teaching and Learning Excellence, and Faculty Senate. As helpful as those efforts were, however, one-on-one work with faculty has had the greatest impact. Rather than just responding to professor's questions about accommodations, the focus is now on helping faculty to view an accommodation request as a signpost that something in the environment is disabling, and brainstorming solutions that improve the learning environment for everyone.

#### Implications

Other universities around the country have been exposed to social model and universal design, and are making necessary changes in their own policies and procedures to reflect this paradigm shift. The UALR DRC's efforts to document specific changes made to date should prove to be helpful to other universities as they embark on a similar journey. The literature review clearly revealed that there is the need for scholarly writing—both anecdotal and research-based—in this area.

As disability resource professionals frame their role as the designers of the service environment, the focus shifts toward creating a usable, equitable environment in the disability office and beyond. In doing so, the disability office becomes a model of universal design and the social response to disability. This role offers great potential for facilitating and sustaining change on the campus at large.

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### **About the Authors**

Melanie Thornton is the Director of Project PACE and the Associate Director of the Disability Resource Center at the University of Arkansas at Little Rock. She has over 20 years experience working in the field of disability with 10 of those years in the higher education setting. She has presented at numerous conferences, has consulted nationally and internationally and has authored and co-authored several articles and a book chapter. Melanie services AHEAD through the Universal Design Leadership Initiative.

Sharon Downs serves as the Director for the DRC. She develops and recommends policies and procedures that promote inclusion and universal design in UALR programs and facilities; coordinates ongoing efforts to have a fully accessible built environment at UALR; provides training and technical assistance to faculty, staff, administrators, and students; and oversees the general direction of the department. She received her Master's degree in rehabilitation counseling from the University of Arkansas, and her Bachelor's degree from the Interpreter Education Program at UALR. She has been involved in the profession of interpreting since 1993, taught in the Interpreter Education Program at UALR for several semesters, and is RID certified. Sharon has presented at many national and international conferences, including the International Technology and Persons with Disabilities, the Registry of Interpreters for the Deaf, and the Association on Higher Education And Disability.

### **PRACTICE BRIEF**

# Bridging the Gap Between Disability Studies and Disability Services in Higher Education: A Model Center on Disability

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#### Abstract

The professional field of Disability Services in Higher Education and the academic discipline of Disability Studies share a perspective on disability that considers disability as a socially constructed phenomenon. Despite this common underpinning, there has been little effort or inquiry into the ways that disability services and Disability Studies can and should inform each other. At the University of Arizona, a model Center on Disability is taking shape that will explore the gaps between Disability Studies and services. Specifically, the Center will unite current and needed resources to advance theory and practice in disability-related research, teaching, and service that contribute to social change. The Center will be a catalyst for innovative, collaborative inquiry that will illuminate the intersections among education, the humanities, the arts, social and behavioral sciences, and the professional schools. The Center's research will address education, policy, and practice.

Over the past twenty years, great emphasis has been placed on improving the quality of service delivery to individuals with disabilities participating in higher education. As the primary professional association for disability service professionals, The Association on Higher Education And Disability (AHEAD) has clearly articulated a mission and values that reflect disability as socially constructed and resulting from "the interaction between person and the environment" (Welcome to AHEAD, 2009). Further, AHEAD has developed and endorsed a code of ethics, program standards, as well as professional standards of practice-all of which consider the importance of redesigning the campus environment to be as accessible as possible. This movement has occurred as a result of many factors including evolving public policies, advocacy by the Independent Living and other disability rights movements, as well as knowledge and theories arising from the academic discipline of Disability Studies.

It is noteworthy that as civil rights for individuals with disabilities were advancing into the national consciousness, the academic discipline of Disability Studies was emerging. Linton (1998) has summarily explained Disability Studies as follows:

Disability Studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations. The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state. It is an interdisciplinary field based on a sociopolitical analysis of disability and informed both by the knowledge base and methodologies used in the traditional liberal arts, and by conceptualizations and approaches developed in areas of the new scholarship. Disability Studies has emerged as a logical base for examination of the construction and function of "disability." (p. 2)

As the professional association for Disability Studies academic programs and scholars, the Society for Disability Studies (SDS) has as its mission to

promote the study of disability in social, cultural, and political contexts. Disability Studies recognizes that disability is a key aspect of human experience, and that the study of disability has important political, social, and economic implications for society as a whole, including both disabled and nondisabled people. Through research, artistic production, teaching and activism, the Society for Disability Studies seeks to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to advocate for social change (SDS Mission, 2009).

The professional field of Disability Services in Higher Education and the academic discipline of Disability Studies share a perspective on disability that considers disability as a socially constructed phenomenon. Despite this common underpinning, there has been little effort or inquiry into the ways that disability services and Disability Studies can and should inform each other. It should be noted, however, that this shared perspective on disability is recent. Historically, disability services was administered and staffed by predominantly nondisabled professionals who sought to be experts in disability conditions, and to provide accommodation, rather than address accessible design of the higher education environment. Disability Studies has from its inception considered disability to be socially constructed, emphasized the insider as expert, and focused interventions on the environment.

#### Problem

Locally, nationally, and internationally, there exists a need for truly innovative, collaborative inquiry in education, careers, and life designed to advance access for people with disabilities. Institutions of higher education are not only catalysts for social change, but also serve as engines of economic development, and are at the vanguard of inquiry and generation of knowledge.

Despite over thirty years of our collective desire and efforts to throw open the doors to higher education opportunities and experiences for individuals with disabilities, they are often considered the poorest, least employed, least educated minority population in the United States. The 2007 Current Population Survey (Bjelland, Erickson, & Lee, 2008) which defined persons with a disability as "those who have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do" reported:

- 28.6% of men and women, aged 18-64 with a work limitation in the United States lived in families with incomes below the poverty line, compared to 9.2% of men and women aged 18-64 without a work limitation who lived in families with incomes below the poverty line;
- In the year prior to 2007, the median household income among civilian, non-institutionalized men and women without a disability, aged 18-64 in the United States was \$60,000 compared to \$30,900 among civilian, non-institutionalized men and women with a disability;
- In the year 2008, approximately 17.6% of civilian, non-institutionalized men and women with a work limitation, aged 18-64 in the United States were employed, compared to 77.7% of those without a work limitation.

The 2007 Annual Disability Status Report (Erickson & Lee, 2008) utilizing "American Community Survey (ACS) data—a US Census Bureau survey designed to replace the decennial census long form" reported that:

- The difference in the percentage working fulltime/full-year between working-age people with and without disabilities was 35.5 percentage points;
- The gap between the employment rates of working-age people with and without disabilities was 42.8 percentage points;
- In 2007, the percentage of working-age people with disabilities with a Bachelor's degree or more in the US was 12.5%;
- In 2007, the percentage of working-age people without disabilities with a Bachelor's degree or more in the US was 30.8%.

Clearly, while the numbers of individuals with disabilities participating in higher education are increasing, there remain significant gaps as evidenced above. To be able to understand and articulate these gaps, we must begin to apply the theories and knowledge emerging from Disability Studies to the way that universities frame and respond to disability in academic, research, and service efforts. This is a necessary first step, if a university is truly to serve as a catalyst for social change, an engine of economic development, and remain at the vanguard of inquiry and generation of knowledge.

As professionals in disability services, we have long considered the ideological shift from solely providing individual services to a balance between these services and facilitating systemic and environmental change. We must ask ourselves important questions such as:

- What is the meaning we make of disability, and how may this inform our practice?
- What is the relationship between knowledge and theories emerging from Disability Studies and Disability Services in Higher Education?
- What is the role of each in examining how addressing disability in its full complexity can promote the full participation, self-determination, and equal citizenship of people with disabilities in society?
- What can we learn about how services that support persons with disabilities, in conjunction with social, legal, and political change, can increase or reduce sources of disempowerment?
- How can disability services make an impact on institutions of higher education, such that individuals with disabilities are seen as inherently valuable to our economic, educational and employment environments?

#### The Center on Disability Model

#### **Partner Structure**

To address the above questions, The University of Arizona (UA) is creating a Center on Disability that will unite current and needed resources to advance theory and practice in disability-related research, teaching, and service that contribute to social change. The Center will be a catalyst for innovative, collaborative inquiry in Disability Studies, Rehabilitation, Deaf Studies, and Disability Services that will illuminate the intersections among education, the humanities, the arts, social and behavioral sciences, and the professional schools. The Center's research will address education, policy, and practice.

The Center on Disability brings together the Disability Resource Center staff and services with the faculty and academic specialties of the Rehabilitation program, including Deaf Studies. As envisioned, the center would be the first of its kind in the country, pairing a premier Disability Resources program in the United States with nationally ranked programs in Rehabilitation and Deaf Studies. This partnership would implement a Bachelor's degree in Disability Studies and pursue a research agenda driven by Disability Studies' concepts.

The UA has a long standing institutional commitment to improving access to higher education for individuals with disabilities. As a result of this commitment, Disability Resources leads the campus and the profession in the pursuit and implementation of well-designed, and accessible campus learning, working, physical, and information environments. It also promotes a view of disability that places it in social, cultural, and political contexts. While the traditional role of a disability service office is the provision of reasonable accommodations to disabled students, Disability Resources at the UA has taken a lead role in also serving disabled faculty and staff, as well as engaging in innovative programs and partnerships. Additionally, Disability Resources has a state-of-the-art adaptive technology lab and offers five competitive athletic teams, a training center, and an equipment repair shop. This array of services and programs exceeds that of any other institution in the United States. Disability Resources staff are recognized locally, nationally, and internationally for their service to the profession and are frequently sought after for presentations, consultation, and formal program evaluation.

The Rehabilitation Counseling Master's Program ranks 5th nationally (Rehabilitation Counseling Rankings, 2010). Rehabilitation's mission is to develop and offer rehabilitation education, research, and community services of excellence that will lead to leadership and practice at the forefront of the rehabilitation field. Rehabilitation graduates hold leadership positions locally and nationally. The majority of administrative leadership positions in the Arizona Rehabilitation Services Administration and in the University of Arizona Disability Resources are graduates of the UA Rehabilitation Counseling Master's degree program. To meet its land grant mission, the Rehabilitation program generates significant levels of grant funding which provides tuition and stipend support to the majority of its students. Through collaboration and recruitment efforts, a very diverse student population containing high percentages of people with disabilities and from minority backgrounds has been attained. Through grant funding, Rehabilitation also conducts state-wide training needs assessments for community rehabilitation programs and provides specific training to meet these needs.

The Deaf Studies program offers a Bachelor's degree in Special Education and Rehabilitation. Deaf Studies students must become fluent in American Sign Language and complete coursework in the areas of history, culture, and language of the deaf community. The Educational Interpreting emphasis in Deaf Studies is nationally recognized as one of the premier programs in the country. Graduates from this program have obtained the highest scores on the Educational Interpreter Performance Assessment in the United States. The Deaf Studies program has also received funding from the Arizona Commission for the Deaf and Hard of Hearing for a state-of-the-art interpreter training laboratory with laptops, a teacher work station, and designated lab space in the College of Education. The program faculty are involved at the national and international levels in the fields of deafness, sign language, and interpreting.

#### Goals, objectives and support of institutional mission

The Goal of the Center on Disability is to create the premier interdisciplinary center in the world for uniting theory and practice in disability-related research, teaching, practice, and service that contributes to social change. Objectives of the Center are to:

- Conduct theory-to-practice research in disability-related academic and service fields;
- Serve as a catalyst for innovative, collaborative inquiry;
- Promote innovative teaching in disability by encouraging faculty to include Disability Studies perspectives into the courses they teach;
- Promote interdisciplinary disability-related research and teaching among the Colleges of Education, Humanities, Social and Behavioral Sciences and Law, and the Health Sciences Colleges of Nursing, Medicine, Pharmacy, and Public Health;
- Generate external funding in support of the Center's mission;
- Offer research opportunities for faculty and graduate students to enhance the understanding of scholarly work and careers in Disability Studies and disability-related areas;
- Disseminate knowledge through a wide variety of formats including guest speakers, conferences, study groups, brown-bags, exhibitions, lectures, symposia, and artistic performances

to University and public audiences;

- Continue to exceed University land grant obligations via Rehabilitation academics and disability services delivery;
- Advance universal access for people with disabilities in education, careers, and life.

The Center on Disability's goals and objectives, while specific to disability, parallel the University's strategic aim to "provide a comprehensive, high-quality education that engages our students in discovery through research and broad-based scholarship." (The University of Arizona, 2010) In meeting the objectives as detailed above, and in support of the institutional mission, the proposed Center will:

- Create, strengthen, and support disability-related research, education, practice, and service through collaborations across departments and programs, both within and across colleges, and campuses;
- Create synergies and leverage resources in the University's recognized areas of expertise;
- Create a culture that supports the success of all members of the University Community;
- Include national and international perspectives, policies, literature, culture, and history with an aim of placing current ideas about disability within their broadest possible context;
- Augment understanding of disability in all cultures and historical periods, and contribute to social change;
- Inform public policies, practices, service delivery systems, educational institutions, and applied fields;

The Center on Disability, will be an integral part of the University of Arizona mission "To discover, educate, serve and inspire" (About the UA, 2009), and furthers the vision of an inclusive society which supports the attainment of academic, professional, and personal goals for all persons. The UA is uniquely positioned to house the premier Center on Disability. The University has a long, rich history of fostering disability-related programs and services that have attracted an increasing number of students and faculty from around the world to Tucson. As reflected by its esteemed national ranking, Rehabilitation has been a leader historically and today continues to advance the field. Finally, faculty and staff from across campus have shown a long-standing commitment to crossdisciplinary research and inquiry, especially in cultural, ethnic, gender, and area studies, and in strengthening the university's ties with the larger community.

Collaboration across the four program areas of the Center–research, practice, service, and education-is governed by a Disability Studies perspective that supports universal access for all individuals in our society. The Center's emphasis on teaching, research and scholarship, active learning, and service further fulfill its mission of an inclusive society which supports the attainment of academic, professional, and personal goals for persons of all abilities.

The Center's activities will enhance faculty efforts to attract high quality students from diverse backgrounds to study at the University and to develop skills to become leaders in disability-related research, education, and practice. The Center on Disability will unite theory and practice in disability-related research, teaching, and service that contribute to social change. The Center's mission: "to help ensure an inclusive society which supports the attainment of academic, professional and personal goals for persons of all abilities" is an integral part of the University of Arizona mission. The mission also reflects the Arizona Board of Regent's strategic directions related to enhancing the quality of student education and enhancing research and impact on economic development.

#### Outcomes

Building a first of its kind Center within a large research-extensive university requires tremendous collaboration, time, and financial resources. Stakeholders at the UA have spent several years meeting with faculty from various disciplines to promote the concepts of Disability Studies; teaching various classes in support of our center agenda; participating in the design and implementation of research; collaborating on grant applications; and serving on local, state, and national boards.

While the economic downturn affecting the State of Arizona has limited the immediate availability of financial resources to the creation of the Center on Disability, the synergy and collaboration between stakeholders has resulted in many accomplishments that may not otherwise have happened. Examples of Center activities from the past year include:

• Receiving Congressionally directed funding for

a Disabled Veterans Education and Reintegration project. This project includes research, program development, and program evaluation components.

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- Submission of a grant application to the National Science Foundation - Research in Disabilities Education, Division of Human Resource Development. In collaboration with the Department of Teaching and Teacher Education, this proposal would examine the impact of the middle school science classroom environment on the motivation and achievement of students with disabilities in science, technology, engineering, and math fields.
- Collaboration with the Sonoran University Center of Excellence in Developmental Disabilities (UCEDD) in teaching, research, and service. Examples of collaboration with the UCEDD are wide ranging from pre-service training workshops for students in medicine, public health, nursing, and law, to replication of a national best practice model school-to-work program for youth with disabilities.
- Development and delivery of new Disability Studies curriculum in the College of Education. Courses have been developed and delivered, such as Introduction to Disability Studies and Services, Disability Perspectives and Narratives, and Mass Media and it's Construction of Disability
- Arizona Board of Regents approval for the further development and implementation of a Bachelor's degree in Disability Studies.
- Co-sponsored with the University Poetry Center, the Tucson Poetry Festival that, among other artists, featured Deaf Poet Ayisha Knight.
- Collaborated with the DIRECT, the local Independent Living Center, on the submission of a grant to improve college access services to low-income individuals with disabilities in southern Arizona.
- Invited Disability Studies scholars to the University to lead faculty development workshops.
- Designed and delivered in-service workshops for Disability Resource Center staff. Discussion topics included power and privilege, the construction of Disability, and how the ways we frame difference impact the man-

ner in which we design and deliver services.

As the Center on Disability at the UA has evolved, it has been continuously met with enthusiasm. Senior administrators are increasingly supportive of interdisciplinary endeavors that reach across old divisions. Such broad collaborations serve to generate new knowledge and hold the promise of solving society's problems and improving our collective well-being. On a practical level, joining together disparate areas remains difficult, yet has already resulted in synergies that are furthering the University and the State of Arizona as leaders in the fields of Disability Studies and Disability Services.

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### **About the Authors**

Dr. Alan Strauss is currently an Assistant Director of Disability Resources at the University of Arizona, coordinating services related to disability and employment. He is also an Adjunct Assistant Professor in the College of Education's Department of Disability and Psychoeducational Studies and a co-investigator with the Sonoran University Center of Excellence in Developmental Disability (Sonoran UCEDD) where he provides leadership in achieving goals related to developing an interdisciplinary degree in Disability Studies, and to increasing employment opportunities statewide for individuals with disabilities. Dr. Strauss has presented widely on disability services in higher education, as well as on the intersection between disability studies and disability services.

Amos P. Sales is Professor of Rehabilitation and Head of the Rehabilitation Program in the Department of Disability & Psychoeducational Studies. He is an Arizona licensed psychologist, Certified Rehabilitation Counselor (CRC) and a National Certified Counselor (NCC). He is past-president of the National Rehabilitation Association and the National Council on Rehabilitation Education, and currently serves as Co-Chair of the National Standards Review Committee of the Council on Rehabilitation Education.

### **Book Review**

### Irene Carter University of Windsor, Ontario

S. E. Burgstahler, & R. C. Cory (Eds.). (2008). Universal design in higher education: From principles to practice. Cambridge, MA: Harvard Education Press, 308 pp., \$32.95 (paperback).

In this book, 41 scholars, practitioners, and students, representing 26 postsecondary institutions, share their perspectives on Universal Design (UD) in higher education. Editors Sheryl Burgstahler and Rebecca Cory support UD as a promising approach by addressing issues of inclusiveness in creating courses, services, information technology, and physical spaces. The complexity of UD in education is explored through the following sections of the book:

- Part 1: Introduction: Universal Design of Instruction in Higher Education
- Part 2: Universal Design of Instruction in Higher Education
- Part 3: Universal Design of Student Services, Physical Spaces, and Technological Environments in Higher Education
- Part 4: Institutionalization of Universal Design in Higher Education

In Part 1, Burgstahler reminds us that Marc Harrison's original "idea that products and environments should be designed for people of all abilities" was coined Universal Design (UD) in the 1970s by Ronald Mace (p. 6). Viewing UD as a promise for making educational products and environments more inclusive, Burgstahler suggests that UD simultaneously addresses equality and accessibility. Burgstahler distinguishes accommodation as an adjustment to make a product or environment accessible, noting this approach is reactive, based on the medical model of disability. In contrast, she describes UD processes as proactive in ensuring access, consistent with an understanding of disability as a social construct (Oliver, 1990). She views infusing UD into all aspects of higher education as a step toward destigmatizing disability, while making all members of a campus community feel welcome. Thus, this chapter sets the stage for the rest of the book by declaring that practicing Universal Design in Higher Education (UDHE) goes beyond accommodation in making institutions more inclusive.

In Part 2 (Universal Design of Instruction in Higher Education), 12 contributors in Chapters 2-13, share perspectives on Universal Design in Instruction (UDI). The authors of Chapter 2 provide an overview of approaches to applying UD. They recommend we tailor the following seven principles of UD to instructional design: equitable use, flexibility in use, simple and intuitive, perceptible information, tolerance for error, low physical effort, and size and space for approach and use. Specifically, Chapter 3 presents suggestions to provide alternative representation of lectures, such as videotapes, website postings of student responses, and the use of interpreters. Similarly, Chapter 4 describes how to implement UDI in a first year course, providing multiple formats for conveying information and assessing learning that creates welcoming classrooms and communicates clear expectations. Chapter 5 outlines elements of Universal Design of Assessment (UDA), suggesting that challenges for UDA include increased expectations for high quality assessments, limited support for faculty, and the lack of knowledge of assessment and test-development techniques. In addition, Chapter 6 recommends the use of information technology and flexible, engaging, accessible course materials.

Chapter 7 focuses on how UD reduces barriers for students with invisible disabilities, while Chapter 8 provides an example of how to develop inclusive environments through a teaching and learning center. Providing strategies through Universal Course Design (UCD), Chapter 9 highlights implementation of easy concepts and sustainability by using a team approach. Chapter 10 stresses UD is simply good teaching where success depends on the significant role of faculty teaching and learning centers. Additionally, Chapter 11 employs case studies as a strategy to support faculty reflection and application of Universal Instructional Design (UID). Chapter 12 describes the early stages of the federally funded Higher Education Disability Support-Universal Design Principles (HEDS-UP) project, designed to introduce change through UD. Chapter 13 ends Part 2 on UID by suggesting that success at meeting the needs of most students is a result of seeking regular feedback from students.

In Part 3 (Universal Design of Student Services, Physical Spaces, and Technological Environments in Higher Education), Chapter 14, Burgstahler notes strategies for applying UD to student service units in institutions of higher learning. Four administrators and three students in Chapter 15, respectively, share experiences with UD and student services. They provide information on how to use UD to make residential life programs, counseling centers, career centers, as well as campus orientation days welcoming, accessible, and usable for everyone.

In Chapter 16, Burgstahler provides strategies for applying UD to physical spaces in postsecondary institutions. These strategies include identifying the space, defining the universe, involving the consumer, adopting guidelines or standards, applying guidelines or standards, planning for accommodations, training and support, and evaluation.

Chapter 17 stresses how the physical environment affects how people feel and behave, influencing how well students interact and learn. Sharing the history of applying UD to information technology, in Chapter 18, Burgstahler promotes strategies for applying UD to technological environments. She explains how IT can level the playing field between diverse and majority students, reminding us the Web has always applied UD principles universally.

Chapter 19 contains information about tools to help developers make their Web pages accessible, proposing that institutions supply faculty with user-friendly software. The contributors to Chapter 20 inform us how three educational institutions set up universally accessible computing labs, suggesting ways we can ensure access to all students.

The final four chapters in Part 4 (Institutionalization of Universal Design in Higher Education), present strategies for institutionalizing UD, promoting accessible and usable instruction, services, physical spaces, and technology.

In Chapter 21, Burgstahler and Cory explore motivations to set up UD. Stressing the need for a paradigm shift, they suggest that demographics, marginalization, equity, shortfalls and strengths, mandates and values, and cost justify a change from the accommodation model to the UD model.

The contributors to Chapter 22 suggest securing administrative support, needs assessment of faculty, student feedback, and a task force as essential to overcoming the barriers of buy-in and restricted funding. Adding to this perspective, Chapter 23 suggests institutions decide on a strategy for implementation, develop training using several formats, and create incentives for faculty participation.

Considering factors that promote Universal Design in Higher Education (UDHE), in Chapter 24, Burgstahler stresses that UDHE has yet to be widely embraced by institutions of higher learning. She assumes that while institutions with a narrower vision of diversity are less likely to embrace UDHE, institutions that focus on broad institutional values and goals, such as equity, diversity, and inclusion, are more likely to promote UDHE.

This book is a valuable resource with excellent examples for faculty and administrators in secondary institutions aspiring to achieve accessibility and inclusion by reaching all students. Burgstahler and Cory go beyond simply describing how to set up instructional strategies by relating UDHE accessibility and social justice as reflected in the social model of disability (May, 2005). Many of the contributors stress how UD encompasses instructional, physical, and institutional changes that overcome present barriers with strategies that are proven and easy to set up.

Many of the contributors reaffirm good teaching practices with several references made to supportive university departments that have had a positive impact on teaching, such as Centers for Teaching and Learning, and Student Disability Services. They provide an understanding of how to produce classroom materials and environments flexible enough to accommodate different learning styles. Acknowledging the challenges faced by faculty and institutions over the past two decades in setting up UD, they suggest motivating reasons for administration to support faculty in transforming teaching practices and physical spaces.

Subsequent in-depth discussion and research needs to further address the authors' appreciation of UD as a potential retention strategy. Showing how UD reduces barriers for all students to a successful university education, the contributors make it obvious the next step is to encourage all faculty and postsecondary institutions to commit to UD. Their conclusions are supported by those recommending ongoing research on UD applications to support their validity (McGuire & Scott, 2006). Burgstahler and Cory conclude that widespread implementation of UD will take structural changes, continuing professional development opportunities, and institutional accessibility policies.

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### About the Author

Irene Carter is an Assistant Professor at the University of Windsor, Ontario, and teaches in the School of Social Work and the Disability Studies Program. At the University of Windsor, Irene helped to develop and to inaugurate the Disability Studies Program, launched in September, 2008. Her 25 years of experience includes teaching positions at Dalhousie University and Mount St. Vincent University, Halifax, Nova Scotia, and management of program development and service delivery for individuals with disabilities. Irene's scholarship focuses on intellectual and developmental disabilities, self-help groups, social support, and curriculum development for Disability Studies.

### **Book Review**

### Marcy Epstein Baker College

S. Gabel, & S. Danforth (Eds.). (2008). *Disability and the politics of education: An international reader*. New York: Peter Lang Publishing, 696 pp., \$129.95 (hardcover)

Gabel and Danforth's (2008) new collection, *Disability & The Politics of Education: An International Reader* is years overdue among disability educators and students. In lieu of the standard desk reference on helping the needy or standardizing education by Western norms, this reader encourages researchers, teachers, students, families, activists, communities, agencies, and governments to assemble and "demand a politics of solidarity" that leads to tangible change and validation of disability in education.

The editors' introduction discusses some structuring international events that have happened since the Education for All (EFA) initiative nearly twenty years ago. These include the UNESCO-led meeting in Jomtien, Thailand, that established basic goals for quality improvement; attention to disabled children ("Children with special needs") and regular schools (of an "inclusive orientation") in the 1994 Salamanca Statement, in Spain; the 2000 Dakar Framework for Action, in Senegal; and the 2007 United Nations convention on the Rights of Persons with Disabilities. On this basis, the editors establish an extremely challenging picture for children and teens with disabilities, including major Western powers such as the United States; disabled parents, teachers, and other stakeholders in inclusive education do not quite understand the disability experience at school.

Four sections, each with a short useful précis, organize numerous voices from within disability scholarship and education that negotiate these difficult questions. A nice touch to these overviews is the cross-reference to related chapters in other sections. Section I, "Inclusive Education," features established authorities on inclusion in education. Beth Ferri explores the ethics of full participation in family-model learning environments that have evolved since the passage of National Law 188 and its philosophy of *intergrazione selvaggio* (wild integration—now a favorite term of mine). Roger Slee, Linda Graham, and Julie Allan, whose negotiation of the rhetoric, personnel, and management of inclusion by those also responsible for social exclusion is simply illuminating.

These formal investigations are nicely offset by the wealth of phenomenological inquiry from lesser known scholars of international education whose voices are integral to the reframing of such questions. Clear analysis of what they see in the "inclusive" but striated classroom only shows the disparity between national ideal and non-existent teacher training. For example, Jagdish Chander and Susan Gabel ponder the problems of counting people and defining disability in the "vibrant democracy" and "religious society" of India. "Impairment," for example, is Karmic, disability often viewed as fatalistic, not socially constructed. Many educators will want to include any and all of the articles in Section I about how we present "inclusive education" as a conduit to validating disability as culture and experience rather than diagnosis or deviance. Perhaps this information could pair well with the broader concepts of inclusive education research, perspective, and disciplinary shift drawn out in Chapters 6, 7, 8, and 9.

Section II on "Policy" examines the impetus and inertia around disability movements across the globe. Chapters 15 and 18 round out this section in somewhat contrastive fashion, suggesting the original divide between practice and praxis. "Theorizing Disability" (Section III) is perhaps the most intentionally troubling section of the Reader, in the same sense as troublemakers disturb "the order of things and can become viewed as problems" (pp. 333-34). Troubling the waters of educational practice, disabled students who (re)present problems, theoretical intersections that sit or do not sit well: theories about disability can't be spelled without trouble. "Higher Education," the interesting fourth section that rounds out the collection, reminds me of how vast Gabel and Danforth's project actually is. Higher education, as the précis makes clear, is highly dependent on the variety of international culture, with North America providing more and more avenues toward accessible college and university education, and—on campuses nationally in Canada and the United States providing support and culture for disabled students from admission to graduation to career.

The volume concludes with four appendices of useful history and polity for the higher education classroom. Articles from major documents such as the World Declaration on Education for All, and World Declaration on Higher Education for the Twenty-First Century: Vision and Action are selected, as are complete texts from the 2000 World Education Forum in Senegal and the 1994 World Conference on Special Needs Education, known as "The Salamanca Statement." I only wish we were given excerpts from the international papers and meetings mentioned in several body articles, since this would have made an already ample text a definitive source for political, historical, and scholastic perspectives. Again, here we have lots to learn from an international discourse of solidarity.

Nonetheless, the voices of report, dissent, and solidarity in *Disability and the Politics of Education* come together as a major accomplishment. The text represents the beginning of an important paradigm shift in disability studies and education. From the plethora of diverse voices of disability here, this paradigm allows for more invention among educators, more wide-ranging information for educational researchers, more inclusive models for inclusive education, and the hope that there could be solidarity among us—a brilliant school for all—still to be forged.

# About the Author

On sabbatical, Marcy Epstein was an associate professor of English and developmental education at Baker College in Flint, Michigan, and currently serves as Past President of the Canadian Disability Studies Association. Her books include *Deep: Real Life with Spinal Cord Injury* and *Points of Contact: Disability, Art, and Culture.* She studies trauma and literacy.

# Appendix A

### Selected Resources and Readings: Disability History, Culture, and Activism

### **Periodicals/Web Resources**

| Disability History Museum         | http://www.disabilitymuseum.org/            |
|-----------------------------------|---|
| Disability Social History Project | http://www.disabilityhistory.org/           |
| Disability Studies Quarterly      | http://www.dsq-sds.org/                     |
| Films Involving Disability        | http://www.disabilityfilms.co.uk/index.html |
| The Ragged Edge                   | http://www.raggededgemagazine.com           |

### Videos

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Rozen, S. (Producer/Writer/Director). (2000). Liebe Perla. [Documentary]. United States: Eden Productions.

### Organizations

Society for Disability Studies c/o Dept. of Disability and Human Development University of Illinois 1640 W. Roosevelt, Chicago, IL 60608-6904 http://www.uic.edu/orgs/sds/

World Institute on Disability, 510 16th St., Ste. 100 Oakland, CA 94612

### Literature

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# Appendix B

### **Guidelines for Disability Studies**

The Society for Disability Studies (SDS) invites scholars from a variety of disciplines to bring their talents and concerns to the study of disability as a key aspect of human experience on par with race, class, gender, sex, and sexual orientation. As a group of committed activists, academics, artists, practitioners, and various combinations of these, we believe that the study of disability has important political, social, and economic import for society as a whole, including both disabled and non-disabled people. Not only can this work help elevate the place of disabled people within society, but it can also add valuable perspective on a broad range of ideas, issues, and policies beyond the disability community, and beyond the study of service provision or the training of providers. Accordingly, we offer the following working guidelines for any program that describes itself as Disability Studies (DS):

- It should be interdisciplinary/multidisciplinary. Disability sits at the center of many overlapping disciplines in the humanities, sciences, and social sciences. Disability Studies programs should encourage a curriculum that allows students, activists, teachers, artists, practitioners, and researchers to engage the subject matter from various disciplinary perspectives.
- It should challenge the view of disability as an individual deficit or defect that can be remedied solely through medical intervention or rehabilitation by "experts" and other service providers. Rather, a DS program should explore models and theories that examine social, political, cultural, and economic factors that define disability and help determine personal and collective responses to difference. At the same time, DS should work to destigmatize disease, illness, and impairment, including those that cannot be measured or explained by biological science. Finally, while acknowledging that medical research and intervention can be useful, DS should interrogate the connections between medical practice and stigmatizing disability.
- It should study national and international perspectives, policies, literature, culture, and history with an aim of placing current ideas

of disability within their broadest possible context. Since attitudes toward disability have not been the same across times and places, much can be gained by learning from these other experiences.

- It should actively encourage participation by disabled students and faculty, and should ensure physical and intellectual access.
- It should make it a priority to have leadership positions held by disabled people; at the same time it is important to create an environment where contributions from anyone who shares the above goals are welcome<sup>1</sup>.

<sup>1</sup> Information retrieved from: http://www.disstudies.org/ guidelines\_for\_disability\_studies\_programs

### Journal of Postsecondary Education and Disability Author Guidelines

The Journal of Postsecondary Education and Disability welcomes submissions of innovative and scholarly manuscripts relevant to the issues and practices of educating students with disabilities in postsecondary educational programs. Manuscripts must be submitted electronically via e-mail to jped@ahead.org

### **Guidelines for authors**:

#### Content

Manuscripts should demonstrate scholarly excellence in at least one of the following categories:

- Research: Reports original quantitative, qualitative, or mixed-method research
- Integration: Integrates research of others in a meaningful way; compares or contrasts theories; critiques results; and/or provides context for future exploration.
- Innovation: Proposes innovation of theory, approach, or process of service delivery based on reviews of the literature and research
- Policy Analysis: Provides analysis, critique and implications of public policy, statutes, regulation, and litigation.

### Format

All manuscripts must be prepared according to APA format as described in The Publication Manual (6<sup>th</sup> ed.), American Psychological Association, 2010. For responses to frequently asked questions about APA style, consult the APA web site at http://www.apastyle.org/faqs.html

- Manuscript length typically ranges between 25 and 35 pages including figures, tables, and references. Exceptions may be made depending upon topic and content.
- Write sentences using active voice.
- Authors should use terminology that emphasizes the individual first and the disability second (see pages 71-76 of APA Manual). Authors should also avoid the use of sexist language and the generic masculine pronoun.
- Manuscripts should have a title page that provides the names and affiliations of all authors and the address of the principal author.
- Include an abstract that does not exceed 250 words. Abstracts must be double spaced on a separate page, or placed in an e-mail request.
- Provide a cover letter asking that the manuscript be reviewed for publication consideration and that it has not been published or is being reviewed for publication elsewhere.
- Tables and figures must conform to APA standards, and must be in black and white only. All tables and figures should be vertical and fit on the page, no landscape format.

#### Manuscripts must be submitted as e-mail attachments in either Microsoft Word or .RTF format to jped@ahead.org

#### Upon acceptance for publication

For manuscripts that are accepted for publication, the following items must be provided to the Executive Editor:

- An electronic copy of the final manuscript as an e-mail attachment.
- A 40-50 word bibliographic description for each author.
- A signed and completed Copyright Transfer form.

Manuscript submissions by AHEAD members are especially welcome. The JPED reserves the right to edit all material for space and style. Authors will be notified of changes.

### **Practice Brief Manuscripts**

JPED will devote a few pages of general issues to a Practice Brief Section to expand the pool of innovative ideas. Practice Briefs will consist of practical strategies and programs used to support postsecondary students with disabilities. The body of the Practice Brief papers will be four pages long (excluding title page, abstract, reference page, Tables, and Figures). The Practice Briefs will not replace the regular research-based JPED papers. They will provide an opportunity for Postsecondary Disability Service staff to share their best practices. To write a Practice Brief for publication consideration, use the following to develop the paper:

- Title page
- Abstract (no more than 60 words)
- Literature Review (no more than two paragraphs, cite references using APA 6th edition style)
- Problem (one paragraph)
- Students and Location Information
- Strategy
- Observed Outcomes
- Implications
- References
- Tables and Figures (if needed)

If any questions, contact the JPED Editor James Martin at 405-325-8951 or e-mail to: jemartin@ou.edu

Send your finished papers via e-mail to: jped@ahead.org for publication consideration. Each Practice Brief will be sent to three postsecondary disability direct service staff for review.