DISABILITY AS A CIVIL RIGHTS MOVEMENT
AND CULTURAL IDENTITY

In order to facilitate student learning, instructors should have a basic knowledge and understanding of the Disability Community as seen from the civil rights movement and cultural identity perspectives. If instructors feel less than prepared, it is probably not unusual, considering that Disability Community issues are not yet a part of most educational programs at any learning level. The following information is offered as a resource to assist teachers in enhancing their own understanding of issues impacting people with disabilities and society as a whole.

The Disability Community

There are approximately 54 million people with disabilities in the United States. That equates to one out of every five Americans experiencing some type of disability. Although by population count this is the largest minority group, members of the Disability Community are not always recognized as a distinct political, economic or social/cultural group. Instead, individuals with disabilities may feel they are separated from one another by medical diagnoses, educational labels, legal definitions, or other terminology that defines functional limitations. There is no one clear definition of what it means to be a person with a disability or who "qualifies" as a person with a disability.

To recognize the Disability Community as a minority group engaged in an ongoing struggle to overcome limiting stereotypes and discrimination, disability studies programs must move away from attempting to categorize and define the community using medical or functional labels. Essentially, the Disability Community is comprised of individuals who experience some type of physical, mental, or sensory difference. The limitations usually implied as part of a definition of disability are largely societal-based.

For example, an individual who was Deaf living on Martha’s Vineyard (during the seventeenth to the early twentieth century) would have experienced minimal limitations in daily life since the vast majority of the hearing and Deaf population communicated using sign language. In contrast, a person who is a burn survivor may have no physical limitations impacting his/her employment skills, but may experience extreme limitations in obtaining or keeping a job due to societal-based limitations of employment discrimination.

At the heart of the Disability Civil Rights Movement is the focus on cross-disability networking and self-advocacy. Ultimately, individuals with a variety of conditions, diagnoses and functional labels share common experiences of
discrimination and marginalization. These shared experiences and the effort to change or fix what is “wrong” with society, whether on an individual or community level, is what defines the Disability Community.

History of Discrimination

Throughout history, people with disabilities have been the target of subtle and obvious discrimination. One of the challenges for the Disability Civil Rights Movement is that this discrimination is often not recognized as discrimination but rather as a "justified" response to the individual's disability. For example, in the fight for accessible public transportation, the lack of access, for people using wheelchairs or having other types of mobility impairments, seemed justified because the person with a disability could not physically board the bus. In some communities, public and private transportation entities refused to provide accessible vehicles. In other communities, transportation was provided through separate door-to-door services that did not operate during the same hours or in the same geographic areas as the existing bus routes. In this situation, the attempt to provide separate services for individuals with disabilities failed to provide equal services. If the same refusal of access, or attempt to justify separate as equal services, targeted members of other minority groups, such as the historic act of sending African American riders to the back of the bus, the “problem” would be recognized as overt discrimination. The challenge for students and instructors using this curriculum is to increase their awareness and recognition of both subtle and overt discrimination.

Several examples of systematic discrimination against people with disabilities exist in the last century. In the early 1900’s, both the United States and Europe promoted the eugenics movement as a humanitarian response to the "tragedy" of disability. During this time, many states had sterilization laws targeting people with certain types of disabilities. Sterilization laws in many states remained in effect until as late as the 1970’s. In Germany, the eugenics movement gained further momentum and people with disabilities were targeted in Hitler's social cleansing. Today, some disability civil rights advocates keep a watchful eye on trends toward legalizing assisted suicide, limiting medical care to children and adults with disabilities, and the use of prenatal testing to determine the presence of disabilities in embryos and fetuses.

Another prevailing method of oppression has been the institutionalization of people with disabilities. Believing that it would be too difficult on families to have a person with a disability in their home, parents of disabled children and adults were advised by doctors, family members, and others to send the disabled family member to an institution. Doctors frequently encouraged parents to abandon their infants with disabilities at birth and leave the children to be raised in a government or charity operated institution. By isolating people with disabilities, there was little need for the community to provide accommodations for them. In
addition, the segregation of people with disabilities was a systematic way of dealing with the human tendency to fear that which is different.

Although the horror stories of large state institutions seem a thing of the past, the Disability Community is still fighting against this method of “caring for” disabled individuals. Today, many Disability Civil Rights Movement actions focus on preventing government and private programs from institutionalizing people with disabilities. Instead, Advocates are working toward providing home and community based programs such as in-home Personal Assistance Services (PAS).

Regarding access to educational services, people with disabilities have historically been denied the right to attend public and private schools. Children and youth with disabilities were often required to attend segregated schools or denied the opportunity to attend public school altogether. In 1975, the Education of Handicapped Children Act, later renamed the Individuals with Disabilities Education Act (IDEA), finally guaranteed that students with disabilities would have access to educational services designed to meet the individual needs of each student in the least restrictive environment. Even with the changes brought on by this legislation, public schools continued to be built without attention to architectural accessibility standards. In addition, students with disabilities and their parents continue to advocate for full inclusion in the school community. Segregating special education classrooms on campus is still an issue in some communities. Finally, educators with disabilities have frequently been denied employment in schools due to lack of accessibility, and discriminatory attitudes.

Other issues of discrimination include a lack of accessible voting places and materials. Although there are a variety of disability civil rights laws addressing this issue, including The Voting Access Act of 1982, many individuals with disabilities still face barriers to voting today. In the area of housing discrimination, people with disabilities were not included as a protected class in The Fair Housing Act until 1988, twenty years after the law first addressed discrimination issues for individuals of ethnic and cultural minority groups.

Protection against employment discrimination in the private sector did not exist until The Americans with Disabilities Act (ADA) became law in 1990. Despite this achievement, several recent U.S. Supreme Court rulings have weakened the effectiveness of the ADA by excluding people with certain types of disabilities such as diabetes; the issue is the court’s interpretation of the ADA’s definition of a person with a disability. To this day, Disability Civil Rights Advocates must address the daunting task of working toward new civil rights victories while continuing the struggle to preserve and enforce existing civil rights legislation.
Disability Civil Rights / Independent Living Movement

An organized response to the historic discrimination experienced by people with disabilities gained momentum in the late 1960's. As individuals with disabilities witnessed other minority groups fighting for their civil rights, they began to organize on their own behalf. Historically there were a variety of disability-specific groups that had advocated for the rights of people with certain types of disabilities. Most of those organizations were initiated by family members of people with disabilities or professionals from the education, social service, and medical fields. Although these organizations were important, they often advocated more for the needs of the family and professionals than the rights and needs of the disabled person. In addition, because most organizations focused on one type of disability, people with disabilities remained isolated from each other. This created an adversarial environment within the Disability Community.

The Disability Civil Rights Movement evolving in the late 1960's was unique in two critical ways. First, people with disabilities created and managed their own advocacy organizations by deciding on their goals and taking action. Then, by taking charge of their own organizations, people with disabilities moved away from the charity based model dominating the existing disability-specific organizations. Disability issues evolved from charity concerns to political civil rights issues. Second, people with various types of disabilities began to join together in their advocacy efforts. It became apparent the old system of disability-specific organizations had separated disabled people from each other. The resulting in-fighting had prevented them from gaining any true sense of power as a movement. By joining together and advocating for the rights of all disabled people, these new organizations did away with the "divide and conquer" influence previously limiting their effectiveness as disability-specific organizations.

Although people with disabilities around the country began to take steps toward creating their own civil rights movement, Berkeley, California is recognized as the "birth place" of the Disability Civil Rights / Independent Living Movement. A group of students with disabilities at the University of California, Berkeley organized one of the first disabled student organizations. This group recognized that they could learn from each other about living independently. They worked to remove architectural barriers on the campus and in the surrounding community. They taught themselves the daily living skills needed to survive. They determined how to hire and train personal assistants to provide the physical assistance they needed. Realizing that all people with disabilities should have access to similar programs, the group opened the first Center for Independent Living (CIL) in Berkeley in 1972.

From the Berkeley CIL, the Independent Living Movement has grown around the country and the world. CILs provide four core services: information and referral, independent living skills training, individual and systems advocacy, and peer
counseling. Several key operating features of a CIL set them apart from other types of disability-related organizations. First, they are consumer-controlled, requiring 51% or more of the staff and the board of directors to be individuals with disabilities. Second, they are cross-disability focused, meaning they do not restrict their programs and services to people with only certain types of disabilities. Finally, they are community-based, non-residential nonprofit agencies designed and operated within a local community. The focus is to work with people to assist them in achieving their independent living goals in their own home and community environments. Many CILs have outreach programs that assist individuals living in institutional settings (nursing homes, etc.) to move to community settings with personal assistance services and other appropriate supports. To learn more about your local CIL, such as the Vermont Center for Independent Living (VCIL) at www.vcil.org, refer to on-line directories found at National Council on Independent Living (NCIL) at www.ncil.org or Independent Living Research Utilization (ILRU) at www.ilru.org.

Disability Civil Rights Laws

As a result of the Disability Civil Rights Movement, people with disabilities and their allies have fought for the passage of many important civil rights laws. In 1973, The Rehabilitation Act became the first major disability civil rights law prohibiting discrimination against people with disabilities in programs receiving federal funding. It set the stage for enactment of the Americans with Disabilities Act. Section 504 of the Rehabilitation Act works together with the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) to protect children and adults with disabilities from exclusion and unequal treatment in schools, jobs and the community.

After the passage of the Rehabilitation Act, the implementation of the law was delayed for years. In 1977, as a response to the delay, Disability Community Advocates staged demonstrations in San Francisco and Washington, D.C. which changed the course of disability civil rights. These demonstrations brought disability advocates together to continue working for cross-disability civil rights. The demonstrations were successful and resulted in the signing of the 1977 Health, Education, and Welfare (HEW) regulations implementing Section 504 of the Rehabilitation Act of 1973.

The 1975 Education of Handicapped Children Act (P.L. 94-142), later renamed The Individuals with Disabilities Education Act (IDEA), recognized the rights of students with disabilities to receive free and appropriate public education in the least restrictive environment (LRE). LRE suggests that children with disabilities are most appropriately educated with their non-disabled peers. Special classes, separate schooling, or segregation of children with disabilities from the general educational environment should only occur if the nature of the child’s disability is such that education in general education classes with the use of supplementary
aids and additional services cannot be achieved satisfactorily. Ultimately, the goal is to include students with disabilities in all aspects of the general education program.

The 1982 Voting Access Act mandated accessible voting places and materials. In 1986, the Air Carrier Access Act recognized the rights of people with disabilities in air travel. The 1988 Fair Housing Amendments Act recognized people with disabilities as a protected class. The most recent major disability civil rights law, The Americans with Disabilities Act of 1990, represents the first time the rights of people with disabilities extended to the private sector in terms of employment and access to programs and services.

An Emergent Disability Culture and Positive Group Identity

In addition to the political advocacy of the Disability Civil Rights Movement, the movement has inspired people with disabilities to begin to view their differences with pride. A sense of Disability Culture is developing as people with disabilities identify and express their differences through various art forms such as dancing, theatre, writing, poetry, music, and visual media. These cultural products not only strengthen the connection people with disabilities have with each other, they also educate non-disabled people to recognize the Disability Community as a source of pride, not pity.

The Politics of Language

In the past, terms such as crippled, handicapped, invalid, and a menagerie of other medical and educational labels were used to describe people with disabilities. Frequently, these terms focused on identifying the disabled person as helpless, ill, or a victim. These labels devalued the person with a disability.

As seen with other minority groups, people with disabilities are now choosing the terms used to describe their differences. The new terms focus on "people first" by describing a person with a mobility impairment, learning disability, etc. Some members of the Disability Community do not focus on "people first" language and instead prefer to identify themselves as "Disabled" similar to other minority groups identifying themselves as African American, Hispanic, or Native American. There are still others who prefer terms such as physically challenged, differently-able, etc.

A non-disabled person might ask how he/she should be expected to keep up with the trends in appropriate language when individuals with disabilities might not even agree on the terms they use. The key to understanding the importance of
language is to recognize that each person with a disability is an individual. Although using "people first" language such as "a person with a disability" is generally accepted, each person has the right to choose how to describe his/her differences. As people of other minority groups might be asked how they choose to describe themselves, also ask the individual with a disability.

A student with a disability may be a female, a middle child, a Native American, a person who has epilepsy, a talented musician, the class clown, and the school’s spelling bee champion. Each of these descriptions explains something that is important to know and understand about the student, but one description alone doesn't define the individual. Ultimately, the most important thing to remember is that “labeling” is not acceptable. Labeling represents a lack of awareness or an attempt to categorize people which leads to stereotyping.