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## Disability and Identity: Personal Constructions and Formalized Supports

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### Introduction

The notion of identity as a personal construction began with the study of adolescents. Erikson (1959, 1968) discussed the various stages that typically developing adolescents go through in the negotiation of self and identity. Throughout the twentieth century, however, collective or group identity has been used as a descriptor and/or political tool for groups typically residing at the margins of society (Duff, 2002). Zinn's *A People's History of the United States* (1990) chronicles political struggles centered in identity politics for: women, people of color, workers, and gay and lesbian groups. Each used identity as a tool for building common culture and empowerment. The concept of identity for people with disabilities is a fairly recent arrival in history. Throughout the past 500 years (and still present to some extent today), people with disabilities have been viewed as mad people, medical maladies, objects of charity, and deviants. Deportation of people with disabilities was the European norm in the 1600's (where the phrase "ship of fools" was first coined) (Focault, 1965, p. 46). Later, when sensory, physical, and cognitive impairments were a focus medical attention, institutional centers were built in Europe (1965) and later the United States. Some of these institutions, though exposed as abusive in nature in the 1960's (Blatt & Kaplan, 1966), are still in existence today (Taylor, 2001). The notions that people with various impairments are broken human beings in need of repair (Shapiro, 1993) and that correct science would fix the problem dominated disability discourse in the North America and Europe until the 1960's and 1970's (Cook, 2001; Ware, 2001).

In a recent study of disability in schools, Mutua (2001) noted how disability is often equated with deviance. In "Policied Identities: Children with Disabilities," Mutua used a case study to demonstrate how, especially for poor families in the United States, deviancy and the notion of disability are congruent with one another. Larger issues of race, poverty, and the inability to function in unsupportive schools create environments where the identity of "disabled" is a professionalized term for "unfit" (Ball, 1994, in Mutua, 2001, p. 296).

Mutua's work is a twenty-first century description of the interchange of the

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professions and those labeled as having a stigmatizing difference. Goffman first laid out arguments about stigma and "spoiled identity" in 1963. His sociological examination into interpersonal exchanges between people with a wide variety of deviances from the norm (non-standard appearance, criminal records, histories of unemployment, and with various impairments) demonstrated that difference was often equated with disdain, indifference, or fear by the larger society. Disabled people, for example, were often viewed as the disability itself, placing the disabled person in the position of either taking exaggerated steps to hide the disability or to join with other similarly stigmatized individuals in groups of support or solidarity.

Friedson (1965) examined Goffman's stigma themes, specifically in terms of the field of rehabilitation. According to Friedson, rehabilitation agencies often consider themselves to be acting in the best interest of their clients. The very notion of client status, however, is stigmatizing. Friedson noted that agencies must define stigma and what needs to be "fixed" in the client in order to remain in business. Rehabilitation agencies (Foucault, 1965, would argue that all professions), then, may become the purveyors of identity for those that they serve.

Modern scholars would argue that such hubris is extending beyond the professions and into the media and entertainment industry. The concept of deviance was noted by Davis (1998) in his article about disabled populations in novels, describing the "villain who is often one-eyed, one-legged, walks with difficulty, stutters, manifests compulsive tics, and so on" (p. 330). Davis' work echoes earlier work by Barnes, Berrigan, & Biklen (1978) who exposed multiple deviant stereotypes of people with disabilities in popular press.

In response to delimiting models and experiences with disability, a late twentieth-century movement began with the intent to shift the disability experience back to people with disabilities themselves. Emerging empowerment models [that could be arguable traced from the 1930's through the Independent Living movements (Shapiro, 1993)] focus on the ontology of disability and critically examine societal barriers to people with disabilities (Peters & Chimedza, 2000). An outgrowth of the emerging models of disability, the notion of disability identity as a personal and political construct, has played a vital role in the empowerment of people with disabilities to shed dependent roles and assert to themselves in society (Lifchez & Winslow, 1979; Shapiro, 1993; Barnes & Mercer, 2001).

This paper will focus on two major issues, with multiple sub-issues relating to disability and identity. First, recent literature pertaining to disability and identity is reviewed. Disability identity, as it appears in the literature, is not a homogenous experience. Rather, multiple definitions and expressions of identity are reviewed and organized into categories of similarity. The purpose of the first section of this paper is to codify the myriad meanings of disability identity as a means of demonstrating its diversity.

The second section of this paper will be a literature review of how disability identity (in its varied definitions) is marginally, yet increasingly supported through institutional legitimization. Formal education, organizations, and communications (i.e., literature and the internet) will be reviewed for their role in promoting disability identity.

### **Disability Identity as a Personal Construct**

The notion of disability in the postmodern world is difficult to specifically place. Global definitions of disability shift across cultures (Ingstad & Whyte, 1995; Peters, 1993), making it difficult for transnational organizations to define the term (Trotter, UStun, Chatterji, Rehm, Room & Bechenbach, 2001).

Thus, the conception of a unitary identity for people with disabilities is impossible (and perhaps undesirable) to codify. Rather, disability as an identity is often a personal construction, a purposive attempt to make meaning of self in the world. A

review of recent literature produced six major categories in which to organize the notion of identity for people with disabilities. These categories: (socially ascribed, disempowering; overcompensating; identities that shift focus away from disabilities; empowerment; complex; and common identity) all additionally have sub-categories. These categories are not meant to limit the possibilities of disability identity but rather to make sense of literature currently available in this area.

### **Externally Ascribed, Disempowering Identities**

Riddell, Baron and Wilson (2001) posit that people with disabilities often have a limited range of identities to choose from because of societal labels and ascriptions. These choices, note the authors, inevitably affect the life choices and future visions of people with disabilities. The authors noted that such limited identity is especially present for people with learning disabilities in an age of lifelong and continuous learning.

Seale (2001) notes that delimited identity may be an outgrowth of the above-mentioned medical model of disability. For example, she describes how people with Down Syndrome often are very much like their family members, from hair and eye color to mannerisms and reactions to external stimuli. Often people with Down Syndrome, however, are first labeled by the Down's descriptor. While some actively choose this association, such associations disempower when they are ascribed. Gabel (2001) cautions professionals in the field of disability to allow people to make their own decisions about membership in disability-related cultures and not to assign identities.

When Gabel gathered data from college-aged students with disabilities, she found that students were often labeled disabled, thus placing a moniker on students that was not necessarily desired. Such labeling causes some to feel "shame" (Murphy, 1990; Snedecor, 2001) about their impairment. Societal stigmas relating to disability often force people to try to hide their impairment, which can produce embarrassing encounters when the impairment is discovered (Williams, 1992).

Such stigma may be a result of societal taboos about disability that openly fear or ignore "imperfection, failure to control the body, ...vulnerability to weakness, pain, and death" (Griffin & Wendell, quoted in Barnes & Mercer, 2001). Such fears and taboos are often reinforced by unfavorable representations of people with disabilities in the media (Thomson, 2001). When identity is assigned by others or by the media, it limits opportunity for self-discovery of identity.

### **Overcompensating Identities**

Once impairments are disclosed, many people feel the necessity to overcompensate in order to cope with the notion of being disabled. Stocker (2001), in her narrative "Disability and Identity: Overcoming Perfectionism" described long periods in her life when she felt the need to succeed at levels higher than her peers without disabilities. This led to a stressful, harried lifestyle, but one Stocker embraced for many years as a means of overcoming her distaste for her disabled identity.

Similarly, one of Gabel's (2001) college students (discussed above) pushed herself to be the top in her class throughout school to cope with the identity of having a hearing impairment. This particular student sought to cope with her impairment by outperforming all of her classmates with non-impaired hearing. Cook (2001) discusses the occurrence of people with psychological impairments take the identity of "survivor" to cope with their disabling conditions, pushing themselves to overcome obstacles.

### **Identities that Shift the Focus Away from Disability**

Much of the literature relating to disability and identity describes how individuals

with disabilities shift the focus of their identity away from personal impairments.

This is for a variety of highly personal reasons and takes shape in several different ways. One way that people shift the focus of their impairment is through denial. Szivos-Bach (1998) found that students with learning disabilities denied their own disability labels as well as had negative attitudes toward others with disabilities in an effort to appear more "normal." Epp (2001) found similar experiences for people with intellectual impairments in Canada. Members of the People First project that had cognitive disabilities often considered themselves to have "some learning problems" but considered people with physical impairments to be truly "disabled."

One of Gabel's (2001) subjects described herself as "impaired," not disabled. This refusal to take the term "disabled" was justified by the student by asserting that she was perfectly capable of almost anything, just slightly impaired in "some ways." In this sense, the word "disability" has a negative connotation.

Similar rejection of the term "disabled" is associated with a large population of Deaf individuals. More commonly known as 'The Deaf', Deaf activists have organized and created linguistic and social bonds known as Deaf Culture. This culture asserts that people who cannot hear and use sign language are a linguistic minority, not a disabled population. As such, the call for greater acceptance of manual communication in society is the focus, rather than the rehabilitation of hearing impairments (Burch, 2001).

Focusing on linguistic issues (for example, the person first and the impairment second) is a tactic used by other groups to direct attention away from disability. The People First movement is an organization of self-advocates, mostly with cognitive impairments. The general notion behind this movement is that the person, not the disability comes first and is therefore the primarily identifiable feature (Epp, 2001). Some of the individuals with Down Syndrome researched by Searle (2001) also felt their personhood was firstly their identity, their disability second. Stocker (2001) sees views as an acceptance of self not as other, but as a human deserving of respect and value, despite levels of perceived achievement. The person-first identity was also widely visible in the Independent Living movements of the 1970's and 1980's. The goal of many in the movement was to dismantle the binary between ability and disability and thus put people themselves at the center of identity discussions (Lifchez & Winslow, 1979).

### Empowering Identities

Unlike identities that seek to overcome or minimize disability as a concept, some disabled individuals place the notion of disability in the foreground of their identities. The placement of disability as a valued concept in identity formation has largely been the result in the shift from the medical to a social discourse on disability. Peters and Chimedza (2000) see disabled identity as the "reclaiming of the body" (p. 248) from models that diminish the value of people with physical disabilities.

Such claims to the body may be in everyday life experiences or in highly intimate matters. Cook (2001) notes that institutions and group living environments for people with disabilities have assumed their clients to be asexual. Cook asserts that people with disabilities must reclaim their sexuality and fight against "societal disapproval of their sexuality" (p. 21). Fleisher and Zames (2001) as well as Lifchez and Winslow (1979) both note the importance of sexuality in the lives of people with disabilities. Tremain (1996) encourages the reclaiming of sexuality to not be limited to heterosexual activity and sites the importance of a gay discourse in disability issues.

While some focus on reclaiming the body, others assert outright pride in their disability. Similar to the way the phrase "black is beautiful" reengineered the way African Americans viewed themselves and their images, so disabled pride sees beauty in disability (Fleisher & Zames, 2001). Fleisher and Zames note that while

most people do not initially wish themselves to be disabled, many assert themselves as important *as* disabled, not important *despite* their disability.

Identities that focus on reclaiming of the body and pride both have distinctly political overtones. An identity that is characterized often in disability literature is the person with a disability as political actor. Fleisher and Zames (2001) provide examples of persons that became disabled during the course of their lives. These people were often politically active before their disability and became active in disability-related politics after they became disabled.

Stacey (1992), a systems scholar, exemplified how identity politics work. The legitimizing language of the politicized identity serves as a communicative tool that asserts that a marginalized group has equal rights in the larger society. Stacey sees this process as one of culture creation, where the marginalized identities legitimize themselves through various tools and thus assert their right to belong in the mainstream culture.

Werner's (1994) *Nada para Nosotros sin Nosotros* chronicles the politicized identity of people with disabilities in Mexico. In his account of disability, charity, and healthcare in developing countries, Werner emphasizes how empowered individuals can make informed choices about services and guide their own rehabilitative efforts. Much of the empowerment is inspired (but does not directly follow) Freirian concepts of raising political consciousness within communities of poor (and in Werner's case, disabled) populations.

The work of Paulo Friere (1970) has recently surfaced again in disability discourse. Friere's *Pedagogy of the Oppressed* was a groundbreaking account of adult literacy classes in Brazil. In these classes, subjects (peasant farmers) were encouraged to describe the world they saw, find their place in it, assess and act upon the injustices they experienced. Such pedagogy has been associated with empowerment politics in Zimbabwe and seen as a transformational praxis for people with disabilities (Peters & Chimedza, 2000).

For some, identity politics can be seen as the claiming of disability as a common signifier (Ware, 2001). Active disabled populations claim themselves as a legitimate minority population that faces societal barriers to civil rights (Fleisher & Zames, 2001). Such claims are meant to be counter-hegemonic to delimiting views of people with disabilities and oppressive policies (Peters & Chimedza, 2000). Though most disabled people do not identify themselves solely as disabled, identity has been a strong political force since the 1930's (see Ware, 2001, for examples from the 1930's; Lifchez & Winslow, 1979, for examples from the 1960's and 1970's; and Shapiro, 1993, for a history of the disabled rights movement in the US).

### **Complex Identities**

As stated above, most people with disabilities do not identify solely with their impairment (Dajani, 2001). Rather, people with disabilities (similar to people without disabilities) identify themselves through multiple descriptors. Additionally, an impairment itself may take on multiple meanings. Fleisher & Zames (2001), citing Wade (1994), noted that disability is at once source of pride or a source of scorn. It is conjointly a catalyst for empowerment and a source of pain.

Riddell et al. (2001) note that disability interacts with gender and social class to form individualized identities based on overall life space. The authors note that disability is part of a milieu of factors that comprise identity. These factors, claim the authors, may either be conscious or unconscious.

Cook (2001) notes three identities with which disabled populations may associate. First is that of the tolerant person, patient with others because they face so many problems themselves. Second is the survivor, the "supercrip" (Shapiro, 1993) that trudges through difficulties. Last is the sensitive person, aware of oppression

because they face it daily. Cook noted that these identities interchange, depending on life circumstances.

Kalekin-Fishman posits that identity is a "median dialectic" (2001, p. 46) that is presented to society and reinforced by dialogue. Such dialogue implies that identity is fluid. Although certain constants are always ingredients to identity (like a particular impairment), identity itself is subject to fluctuations of self and society. These statements corroborate assertions made earlier by Taylor and Bogdan (1989) who note that "the definition of a person is to be found in the relationship between the definer and the defined and is not determined by the abstract meanings attached to the group of which the person is a part" (quoted in Taylor, 2000, p. 84).

### **Common Identity**

Dajani (2001), citing Fine and Asch (1988) note that seventy-four percent of people with disabilities feel they have some sense of commonality. In this case, disability is seen as a common identity or, in many texts, common culture. Barnes and Mercer (2001) describe this common identity as "membership of an oppressed or marginalized group extolling its virtues" (p. 525).

Albrecht, Seelman, and Bury (2001) and Fleischer and Zanes (2001) each dedicated a chapter of their *Handbook of Disability Studies* and *Disability Rights Movement* books to the identity and the common culture of disability. Viewing disability through an anthropological lens, the authors cite several Disability Studies scholars that see the commonalities in the experience of having a disability. Such commonalities produce a common language to codify shared experiences of negotiating disability in a world oriented largely for (and by) able-bodied people (2001).

People with specific impairments also maintain and produce culture. As noted earlier in this paper, Deaf culture is a culture generated for and by people that are Deaf. It has its own language, own expressions and own specific commonalities. Although the notion of deafness as a disability is contested, Deaf culture is one of the strongest and most visible cultures of association in the United States today (Shapiro, 1993).

The ties that bond people with disabilities (the generated culture) often cross lines of gender and social class (Riddell, et al., 2001). Often membership in these cultures is self-defined (Gabel, 2001) and acts as a support mechanism for people with disabilities. Such a support network can be localized in nature or exist with the aid of technology (i.e., the internet) across geographical space (Seale, 2001).

The purpose of disability culture is twofold. First, it produces a sense of belonging within a shared range of experiences (Ware, 2001). Second, it promotes a common voice to assist in the navigation of mainstream macro-culture (Barnes & Mercer, 2001). One of the messages often presented is the inherent value of people with disabilities in a world defined by standardized measures (Reay & William, 2001; Riddell et al., 2001).

Disability culture posits the importance of the disabled experience to the population at large (Fleischer & Zanes, 2001). This experience is sometimes captured through stories of exceptional accomplishment in the media (Thomson, 2001) but is more importantly carried out through everyday examples of people with disabilities and their lives. Rather than focus on exceptional cases, Cook (2001) proposes that people with disabilities generally identify with a culture that knows oppression, knows frustration, and knows how to survive. Although these generalizations are overly simplistic and do not reflect the heterogeneity of disability culture, the notion that different worldviews are important to society is significant. Systems theorists like Margaret Wheatley call this "requisite variety," or the necessary diversity that humanity needs to understand itself and its world (1984).

Identity formation has a wide range of incarnations. It can be ascribed by another and thus delimiting; or it can be self-ascribed and empowering. Some find solace in avoiding the term disability in their lives while others openly embrace the term and identify primarily with it. Such identification has political ramifications, as many activists in disability policy are self-identified as disabled. Individualized identities often seek common identities and thus the notion of disabled culture has grown out of a critical mass of people associating themselves with the disabled experience.

Identity exists at both personal and societal levels. It is most empowering when it is self-described and defined as an individualized experience. When individualized experiences are asserted, communities of common experience grow. Ironically similar to disempowering and socially ascribed identities discussed earlier in this paper, self-defined identity, has recently been reinforced by formal organizations and structures. For lack of a better word, disability identity is becoming "institutionalized." Although the word "institutionalized" has an egregious associational value for the disability community (see introduction to this paper), disability identity is gradually becoming formalized in societal structures around the world.

### **Formal Supports for Disability Identity**

Disability identity is formally supported through three major channels: formal education, organizations for and of people with disabilities, and communications. Each of these channels supports the notion of disability as a self-ascribed identity and the concept of disability culture. While there is still institutional support for the medical and deviance outlooks on disability, there are growing numbers of institutions that support the identity/cultural models of disability, thus playing a role in the dismantling of hegemonic policies and stereotypes toward people with disabilities.

### **Formal Education and Support for Disability Identity**

Formalized education (especially higher education) has been a leader in supporting the notions of disability identity and culture. Disability Studies, as a subject area, has become institutionalized in many universities. This field of study views disability as a multi-disciplinary endeavor, concentrating on the humanities as well as personal and political issues of people with disabilities rather than "curing" the problem of disability (Longmore & Umansky, 2001).

Several universities in the U.S. and U.K. currently offer Disability Studies programs. Universities have dedicated funding to the scholarly pursuit of disability from a multi-disciplinary viewpoint. Many of the academic publications and ethnographic studies of individuals or groups of people with disabilities and their negotiations with society are a result of research from Disability Studies scholars.

In teacher training institutions there is a new, but growing field of "alternative special education" programs. Universities like Syracuse University and the University of South Florida offer such programs. These universities approach special education from a cultural, not rehabilitative standpoint (Ware, 2001).

Gabel (2001) laments, however, that many traditional teacher-training programs do not promote reflection and identity building for their students with disabilities. The author notes that women, students of color and gay/lesbian/transgender students are encouraged to reflect on their role as teachers from the perspective of their gender or cultural identities. Students with disabilities, however, are not encouraged to reflect on disability and teaching. Rather, students often feel the need to suppress their impairment for fear of appearing unmarketable (2001).

Benjamin (2001) found that the notion of disability identity is absent in K-12 education. She places the blame for this omission on standards-based curriculum.

Referring to high academic expectations as the sole desired outcome in schools, Benjamin said that government educationalists delimit opportunities for identity construction because "...they operate according to a new set of assumptions about what counts as educational success, and treat the politics of identity formation as, at best an add-on to the schooling process, and, at worst, an irrelevant distraction" (p. 40).

Despite the lack of awareness in K-12 education, the phenomenon of disability identity has become a lived experience for many. Education, as a field, has begun to address this phenomenon, but on a relatively minimal level.

### **Organizations for and of People with Disabilities**

Organizations for and of people with disabilities can be found worldwide. Such organizations are not focused on cures but on advocating for and empowering people with disabilities from their current life space. Organizations such as the World Institute on Disability, ADAPT-USA, Mobility International, Self-Help Organization of Paraplegics (South Africa), Acceso Libre and Project Projimo (Mexico), and Women with Disabilities (Australia), to name just a few, support and legitimize the causes of people with disabilities as well as support the concept of disabled cultural identity (Barnes and Mercer, 2001).

Additionally, there are some organizations that promote the politics of multiple identities. For example, the Disabled Action Women's Network in Canada addresses issues of both disability and feminism. Disabled Dykes focuses issues of disability and sexuality (Tremain, 1996).

Although some of the organizations listed above are highly professional in nature, many are small groups supported by family members of people with disabilities. Seale (2001) discusses how families are actively involved (but are sometimes overly directive) in the Down Syndrome community. Crockett (2000) notes that the passage of the United States Public Law 94-142 (that guaranteed education for children with disabilities) was the result of highly organized parents, identifying their children as disabled and deserving of education.

### **Communications**

Communications support disability through publications and informal networks (using tools such as the Internet). Publications like North America's *Ragged Edge* and *Mouth* as well as British publications like *In From the Cold* (Barnes & Mercer, 2001) have given voice in press to people with disabilities. Readership includes people with and without disabilities. Other academic journals like *Disability and Society* and this journal chronicle issues relating to the social impacts of disability.

A recent book edited by Albrecht, Seelman and Bury (2001), *Handbook of Disability Studies* is a compilation of work from disability studies researchers around the world. The book is of considerable size (over 900 oversized pages of text) and is one of the most extensive collections of disability studies essays and research to date. All but a few of the articles and books listed in the bibliography of this paper are other examples of institutionalizing the notion of disability identity into society.

A less formal way that disability is promoted and disability culture is generated is across the Internet. Seale studied the self-presentation patterns of people with Down Syndrome on self-created homepages (2001) and found a variety of forms of self-expression and identification. Homepages, listservs, chat-lines, and informational pages are all ways people with disabilities have institutionalized the notion of identity and culture into mainstream society.

### **Conclusions**

The notion of identity as it relates to disability is multifaceted. There are still populations of people with disabilities who live with an identity ascribed to them that



populations of people with disabilities who live with an identity ascribed to them that they do not want. The term "disability" can be stigmatizing and disempowering when it is imposed upon them by others.

Others that live with impairments try to compensate for their limited ability to perform certain tasks. Stocker (2001), for example, spent many years of her life working to overcome her perceived shortcomings caused by her impairment. Only later in life did she come to terms with and begin to "overcome perfectionism" (2001, p. 54).

Epp (2001) studied a third group of people with cognitive impairments. This group shifts the focus of identity away from disability. For example, both Epp (2001) and Szivos-Bach (1993) both found that their subjects denied being identified with the term "disability." Others admit disability, but place the identity of "person" first. In this case, disability becomes a secondary identity (Seale, 2001).

Still other groups employ identity as mode of empowerment. People who choose disability as their primary identity use phrases like "pride" when discussing their disability (Fleisher & Zanes, 2001). Others use disability identity as a moniker for their politicized lifestyle, linking disability issues and politics (2001).

Current disability literature also discusses the complexities of identity. For some, disability itself is a complex issue (2001). Disability and identity can at once be a positive and negative experience. Coupled with other issues, such as gender and social class (Riddell et al., 2001), disability often becomes part of a milieu of identity issues.

Despite complexities, most disabled people still feel a sense of commonality with each other (Fine and Asch, 1988). Such commonalities produce what is commonly called "disability culture" (Fleisher & Zanes, 2001). This culture, borne out of common experience (Ware, 2001), assumes a common voice to address societal barriers (Barnes & Mercer, 2001).

The common voice and other empowering identities for people with disabilities are emergently receiving support by formalized structures. These structures publicize and communicate the notion of disability identity to the larger population. Messages such as: people come before disability, disability as a social and political issue, and promotion of disability culture are found in formal education, organizations and communications.

Formal education at the tertiary level has succeeded in supporting notions of disability via the social sciences and humanities. Disability Studies programs are taking their place alongside other minority study programs at larger universities in the United States, Europe and Australia. Such programs act as focal points for accentuating the diversity of disability and shifting paradigms of disability away from solely delimiting models.

Organizations also have promoted the notion of disability and identity. Many organizations worldwide are comprised entirely of people with disabilities. Others exist for people with disabilities and are run by people with and without disabilities. Organizations focus both entirely on disability and on multi-identity issues such as disability and feminism (Ryan, 2001).

Lastly, publications have institutionalized the disabled identity into mainstream society. Narrative accounts of disability have brought the reality and complexity of disability to a wide readership, some with no previous experience with the notion of identity.

The definitions of disability identity are so varied that it is difficult to posit one clear statement about the issue. Rather, disability identity must be examined as an individualized experience. Disability means different things to different people. While a disabled culture does exist, not all are willing to commit to it. In all cases,

however, identity implies that disability is a difference in lived experience. Such difference shows increasing (albeit slowly) support, value, and understanding by mainstream society.

This article is meant to discuss issues of identity formation. It is not meant to be overly hopeful or optimistic. Barriers still and always will exist for disabled populations. Gradual legitimization of various disability models, however, demonstrates the possibilities for future growth.

## References

Albrecht, G.L.; Seelman, K.D.; & Bury, M. (eds.) *Handbook of Disability Studies*.

Thousand Oaks, CA: Sage.

Barnes, E., Berrigan, C. & Bicklen, D. (1978). *What's the difference: Teaching positive attitudes toward people with disabilities*. Human Policy Press: Syracuse, NY.

Barnes, C. & Mercer, G. (2001). Disability culture: Assimilation or inclusion? In Albrecht, G.L.; Seelman, K.D.; & Bury, M. (eds.) *Handbook of Disability Studies*. Thousand Oaks, CA: Sage (pp. 515-524).

Benjamin, S. (2001). Challenging masculinities: disability and achievement in testing times. *Gender and Education*, 13 (1), 29-55.

Blatt, B. & Kaplan (1966). *Christmas in Purgatory: A photographic essay on mental retardation*. Massachusetts: Scituate Harbor.

Burch, S. (2001). Reading between the signs: Defending Deaf culture in early twentieth century America. In Longmore, P.K. & Umanski, L. (eds.) (2001). *The new disability history: American perspectives*. New York: New York University Press. (pp. 214-235).

Cook, J.A. (2001). Sexuality and people with psychiatric disabilities. *SIECUS Report*, 29 (1), 20-25.

Dajani, K.F. (2001). What's in a name? Terms used to refer to people with disabilities. *Disability Studies Quarterly* 21 (3), 196-209.

Davis, L. (1998). Who put the *The* in the novel? Identity politics and disability studies in novel studies. *Novel* (Summer), 317-334.

Duff, P.A. (2002). The discursive co-construction of knowledge, identity, and difference: An ethnography of communication in the high school mainstream.

*Applied Linguistics*, 23 (3): 289-322.

Durlak, C.M.; Rose, E.; Bursuck, W.D. (1994). Preparing high school students with learning disabilities for the transition to postsecondary education: Teaching the skills of self-determination. *Journal of Learning Disabilities*, 27(1), 51-59.

Epp, T. (2001). Disability: Discourse, experience and identity. *Disability Studies Quarterly*, 134-144.

Erikson, E. H. (1959). Identity in the life cycle. *Psychology Issues*, Monograph 7.

Erikson, E. H. (1968). *Identity: Youth and Crisis*. New York: W. W. Norton.

Fleisher, D.Z. & Zames, F. (2001). *The disability rights movement: From charity to confrontation*. Philadelphia: Temple University Press.

Foucault, M. (1965). *Madness & civilization: A history of insanity in the age of reason*. New York: Random House.

- Friere, P. (1970). *Pedagogy of the Oppressed* (translation by Myra Bergman Ramos). New York: Continuum.
- Friedson, E. (1965). Disability as deviance. In Sussman, M.B. (ed.). *Sociology and rehabilitation* (pp. 71-99). Washington, DC: American Sociological Association.
- Gabel, S. (2001). I wash my face with dirty water. Narratives of disability and pedagogy. *Journal of Teacher Education*, 52 (1), 31-47.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Ingstad, B. (2001). Disability in the developing world. In Albrecht, G.L.; Seelman, K.D.; & Bury, M. (eds.) *Handbook of disability studies*. Thousand Oaks, CA: Sage Publications. Pp. 772-792.
- Kalekin-Fishman, D. (2001). The hidden injuries of the 'slight limp'. In Priestley, M. (ed.) (2001). *Disability and the life course*. Cambridge: Cambridge University Press. pp. 136-150.
- Kliewer, C. & Fitzgerald, L.M. (2001). Disability, schooling and colonialism. *Teachers College Record*, 103 (3), 450-470.
- Lifchez & Winslow (1979). *Design for independent living*. New York: Whitney Library of Design.
- Longmore, P.K. & Umanski, L. (eds.) (2001). *The new disability history: American perspectives*. New York: New York University Press.
- Meyer, L.H. The impact of inclusion on children's lives: Multiple outcomes, and friendship in particular. *International Journal of Disability, Development and Education*, 48 (1), 19-31.
- Mutua, N.K. (2001). Policed identities: Children with disabilities. *Educational Studies*, 32, no. 3 (289-300).
- Murphy, R. (1990). *The Body Silent*. New York: Holt.
- Peters, S. (ed.) (1993). *Education and disability in cross-cultural perspective*. New York: Garland.
- Peters, S. & Chimedza, R. (2000). Conscientization and the cultural politics of education: A radical minority perspective? *Comparative Education Review*, 44 (3), 245-271.
- Reay, D. & Wiliam, D. (2001). I'll be a nothing. Structure, agency and the construction of identity through assessment. In Collins, J. & Cook, D. (eds.) (2001). *Understanding learning: Influences and outcomes*. London: Open University Press. pp. 149-161.
- Riddell, S.; Baron, S. & Wilson, A. (2001). The significance of the learning society for women and men with learning difficulties. *Gender and Education*, 13 (1), 57-73.
- Seale, J.K. (2001). The same but different: The use of the personal home page by adults with Down Syndrome as a tool for self-presentation. *British Journal of Educational Technology*, 32 (3), 343-352.
- Shapiro, J. (1993). *No pity*. Times Books, Random House: New York.
- Snedcor, S. (2001). Personal insights from people with cognitive, emotional disabilities. Epilogue to Cook, J.A. (2001). Sexuality and people with psychiatric disabilities. *SIECUS Report*, 29 (1), 20-25.

Stacey, F. (1992). *Managing the Unknowable*. Jossey-Bass: San Francisco

Stocker, S.S. (2001). Disability and identity: Overcoming perfectionism. *Frontiers*, 21 (2), 154-173.

Szivos-Bach, S.E. (1993). Social comparisons, stigma and mainstreaming: The self esteem of young adults with mild mental handicap. *Mental Handicap Research*, 6 (3) 217-236.

Taylor, S.J. (2000). You're not retarded, you're just wise: Disability, social identity, and family networks. *Journal of Contemporary Ethnography*, 29(1), 58-92.

Taylor, S.J. (2001). The continuum and its current controversies in the USA. *Journal of Intellectual and Developmental Disability*, 26(1), 15-33.

Thomson, R.G. (2001). Seeing the disabled: Popular rhetorics of popular photography. In Longmore, P.K. & Umanski, L. (eds.) (2001). *The new disability history: American perspectives*. New York: New York University Press.

Tremain, S. (1996). *PUSHing the limits: Disabled dykes produce culture*. Toronto: Women's Press.

Trotter, R.T.; UStun, B.; Chatterji, S.; Rehm, J.; Room, R.; Bichenbach, J. (2001). Cross-Cultural applicability research on disablement: Models and methods for the Revision of an international classification. *Human Organization*, 60 (1), 13-27.

Ware, L. (2001). Writing, identity and the other. Dare we do disability studies? *Journal of Teacher Education*, 52, 2 (107-123).

Werner, D. (1994). *Nothing for US without US*. Palo Alto: Hesparian Foundation.

Wheatley, M. J. (1994). *Leadership and the New Science*. Jossey-Bass: San Francisco.

Williams, D. (1992). *Nobody Nowhere*. New York: Avon Books.

Zinn, H. (1990). *A People's History of the United States*. New York: Harper and Rowe.

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