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ABSTRACT
            This report discusses the societal oppression of
people with disabilities and the growing awareness of a new group
consciousness and an emerging disability culture. It examines social
attitudes toward individuals with disabilities; the effects of using
a medical model of disability, with its implications for the
objectification and control of people with disabilities; the movement
of people with disabilities toward a sociopolitical model as members
of a distinct minority group; and the values of this emerging culture
such as accepting a disability as a source of pride and viewing life
with a disability as worth living and celebrating. The functions of a
disability culture are presented, including: (1) providing symbols,
rituals, and values that serve to strengthen personal and group
identity; (2) uniting people with disabilities and experiences,
facilitating group action; (3) empowering people with disabilities by
providing a variety of ways to inform others about themselves; and
(4) inspiring other people with disabilities to self-identify. The
paper also discusses the need for greater societal access and for
stronger implementation of the Americans with Disabilities Act.
(Contains 23 references.) (CR)

Disability Culture, Community, and Pride

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Running head: DISABILITY CULTURE

Disability Culture, Community, and Pride

In the past few decades, people with disabilities have been developing a new group consciousness. This consciousness reflects disabled people's experience of societal oppression, and an emerging disability culture. This culture has the potential to support not only individuals with disabilities, but the larger disability civil rights movement that is gathering strength.

Disabled people live in a society that expresses fear, pity, hostility, and condescension toward them. On one hand, disabled people often experience discrimination in employment, education, housing, and other spheres of life. On the other, they receive treacly praise for being "courageous", or an "inspiration" for nondisabled people (Longmore, 1987). Even when disabled people are functioning to some degree in the larger society, they may not be exempt from oppressive attitudes: There is evidence that the demonstration of competence by people with disabilities may evoke negative reactions by nondisabled people, as though such behavior violates strongly held expectations of what disability represents (Katz, Farber, Glass, Lucido, and Emswiller, 1979). In addition, disabled people are more likely to be targeted for violence than non-disabled people (Waxman, 1991). These mixed responses reflect a profound, highly-charged ambivalence toward people with disabilities in our society.

Despite all of the external, social factors that handicap disabled people, disability is still defined largely by the medical model of disability. The medical model of disability implies that any handicaps experienced by people with disabilities are solely or primarily attributable to the disability, and not to any societal, physical, or attitudinal barriers. It views disability as a biological defect that calls for persistent medical intervention. The ultimate goal of this model is to make the functioning of the disabled person conform to the rest of society, so that she or he may be assimilated (Longmore, 1993).

The dominance of the medical model has profound implications for the experience of people with disabilities. Because of the manner in which it defines disability, social factors that affect the lives of people with disabilities are virtually ignored. Worse, the kind of attention given to disability by people in the medical profession, in social services professions, and other

organizations set up to benefit disabled people institutionalizes oppressive stereotypes of people with disabilities (Holmes & Karst, 1990; Abberley, 1987). One implication of this is the objectification and control of people with disabilities. Rather than being treated as active agents making choices that affect their own lives, disabled people are often subjected to consequences of bureaucratic decisions ostensibly made on their behalf--decisions that may result in less independence and dignity for the disabled person affected. For example, people with disabilities are often forced to live in nursing homes where they are told when to sleep, what to eat, restricted in their ability to leave the home, and sedated so that nursing home personnel can "care" for them more easily. Current policies typically don't provide the kind of in-home attendant services that would allow people with disabilities to live in their own homes, independently, and at far less cost (Shapiro, 1993). Indeed, many people with disabilities regard the agencies and organizations that are set up to serve them as opportunistic and exploitative. These critics point to the huge amount of money devoted medical and other services for disabled people, and suggest that people with disabilities represent a lucrative industry to medical and social service organizations--such that there a strong disincentive for adopting a non-medical perspective of disability (Lane, 1992). Finally, disabled activists challenge organizations like the Muscular Dystrophy Association (MDA) for their reliance on and reinforcement of images of disability that evoke pity toward people with disabilities (Peters, 1985). Arguably, images of disability used by the MDA further popularizes the medical model.

Another function that the medical model serves, like other frames or models, is definitional control (Rosenberg, 1989; Gamson, 1992; Iyengar, 1991). This view of disability implicitly limits the range of beliefs and practices that are considered relevant to disability to those from the fields of medicine, rehabilitation, public policy, and social work. By defining disability as a flaw inherent to the individual, rather than a social construct requiring broader societal change, the focus has been on individual adaptation for the ostensible convenience of the larger society (Longmore, 1993). Rehabilitation of the individual has been one of the means to achieving this, by inducing disabled people to function like nondisabled people. This has taken the form of training people to

walk with crutches rather than use a wheelchair, or teaching deaf people how to speak while suppressing the use of sign language. Even if the rehabilitation does not result in an actual increase in functional ability, effort on the part of the disabled person to at least try to create the appearance of normality has been expected in return for societal benevolence and token acceptance, argues historian Paul Longmore (Johnson, 1989).

Because of its impact at the level of individual persons, the definitional control that the medical model has over disability has posed a serious challenge to the development of a broader disability pride among disable people, and to broader self-identification of people with the disability movement. A primary value implicit in the medical model is that people with disabilities experience a lesser quality of life, and that people with disabilities are unacceptable as they are. Surrounded by this view, people with disabilities are exposed to a social reflection of themselves that is extremely negative. If a person is socialized to view disability as a shameful aspect of the self, then she may internalize this stigma, which may lead her to hide or deny the disability (Johnson, 1987). A person who is ashamed of her disabled status is less likely to seek out like others for support, and to lend her efforts to strengthening the disability movement.

One way of weakening the definitional control that the medical model has over disability is to highlight the socially-constructed nature of that definition. Although the effects of disabilities are often thought to be immutable, "super-crip" and other "overcoming" myths aside, a particular condition may not even be considered a disability in a different time and place. For example, the prevalence of inherited deafness on Martha's Vineyard between 1750 and 1950 led to a situation in which sign language was acquired by every island resident, hearing or deaf (Groce, 1985). Deafness was not considered a stigma, or even to be remarkable in any way. Indeed, deaf people were often the most educated people on the island, and were turned to for leadership, or when an illiterate island resident needed someone to read something for him or her (Groce, 1985). Thus, the social context determines to a great degree if a condition is stigmatized, or if it is even considered to be a disability (Scheer & Groce, 1988; Groce, 1985).

This suggests greater flexibility in thinking about disability than is commonly imagined,

and promotes a socio-political paradigm of disability. The socio-political paradigm provides an alternative, positive view of disability that may serve to eventually lessen the stigma of disability that is reinforced and maintained by the medical definition. This paradigm places the handicap that is associated with disability in a social, interactionist context, rather than within the individual with the disability. It argues for removal of external physical and attitudinal barriers to access for people with disabilities, and de-emphasizes the need for medical cures and fixes.

People with disabilities have been adopting the socio-political model, resulting in efforts to simultaneously develop a community and to influence the larger society's view of disability. This movement is informed not only by the experiences of disabled people, but by the civil rights movements of African-Americans and other minority groups, the women's rights movement, and by the current movement for gay and lesbian rights. As different as the experiences of members of these groups may be, there are commonalties that they all share: Disenfranchisement, barriers to political and economic power, assignment to marginal status in the larger society, internalization of oppression , and struggles for dignity and pride. All of these movements share the objectives of redefining the meaning of the group's identity, of repudiating the stigma traditionally associated with membership in that group, and of demanding equal opportunities within the larger society.

People with disabilities have increasingly viewed themselves as members of a distinct minority group, possessing a unique and valuable culture (Wade, 1992; Cristoph, 1985; Shapiro, 1993). This emerging culture is marked by the development of arts and literature reflecting the disability experience, and by a unique set of values. Disability culture repudiates the negative images of disability that are prevalent in our society, and fosters a positive identity in disabled people (Johnson, 1987). Much of the drive for the formation of a disability culture and community, and for the activism and creativity within this community, stem from the experience of shared oppression, anger; and from the determination to express to the nondisabled world those aspects of the disabled experience that are both affirmative, and counter-intuitive for nondisabled people.

A strong disability culture provides a base from which the socio-political view of disability

can be further developed and extended to the larger public. Disability culture serves several functions. Specifically, Carol Gill argues, disability culture can provide disabled people with symbols, rituals, and values that can serve to strengthen personal and group identity. It can unify people with different disabilities and experiences, providing a supportive environment and facilitating group action. It can empower disabled people by providing a variety of ways to inform others about themselves. Finally, disability culture can inspire other people with disabilities to self-identify as disabled, rather than staying in the shadows (Gill, 1993).

So, what are the values of this emerging culture? First and foremost, that disability can be a source of pride rather than shame (Disabled and Proud, 1993). The aspect of ourselves that marks us as different from the rest of society contributes to making us who we are, thus developing a positive self-identity involves embracing all aspects of ourselves. Rather than viewing a disability as a deficit, we can view it as a part of our whole, complete self. Indeed, Hahn (1988) argues that disability can be viewed as beautiful.

An important implication of this value is that life with a disability is worth living, indeed can be celebrated. It counters the notion that people with disabilities need persistent and invasive medical "fixes" to have a good quality of life, and challenges the implications of the medical perspective for a variety of situations. Disability awareness suggests alternative views of the right-to-die movement, and for the ongoing abortion debate. From this vantage point, disabled writers and social scientists have criticized the readiness of right-to-die advocates to pave the way for assisted suicides for disabled people when social factors contributed heavily to the circumstances that led to the disabled people's expressed desire to die (Shapiro, 1993). This value also calls into question the assumption that a fetus with a disability would necessarily be aborted, and warns that evolving reproductive technologies may be misused as part of a new eugenics campaign. Misusing these new technologies would also serve to further stigmatize people with disabilities (Miringoff, 1991), and would be alarmingly reminiscent of the efforts by the Nazis to eliminate people with disabilities from Germany during World War II (Burleigh, 1990).

Another value within Disability culture concerns the construct of independence. In some

respects, independence is redefined, such that services that make our environment accessible (e.g., personal care assistance, sign language interpretation) are regarded as promoting independence rather than reflecting dependence. Similar to this is the view that adaptive equipment enable a broader sphere of activity, such that one is not "confined to a wheelchair", but "uses a wheelchair" instead. In addition to these redefinitions of what it means to be independent, the construct of independence as it is employed in the American ideal of individualism may be seen as less important in the Disability community relative to an alternative value of interdependence (Chelberg and Kroeger, 1993).

The disability experience, and the values of disability culture have been expressed in a remarkable body of art and literature, in virtually any medium possible. Anne Finger's (1990) book, *Past due: A story of disability, pregnancy, and birth* is a memoir that challenges prejudices against sexuality and parenthood in people with disabilities. "Children of a Lesser God" is a film that depicts the clash between two lovers from different worlds: a Deaf woman who is neither able to nor wants to speak, and communicates in ASL, and a hearing man (who teaches speech to deaf children) who wants her to speak. John Callahan, the Tragic But Brave Road Show, and Comics on Wheels all employ humor to skewer the cherished myths that nondisabled people have toward disabled people, and to educate nondisabled people while making them laugh.

Making allies of nondisabled people is arguably important in the effort to secure greater societal access. But the perspective that nondisabled people can bring when attempting to be allies can backfire. There is evidence suggesting that nondisabled people's ideas of what constitutes positive behavior toward people with disabilities is quite different from those of disabled people. Rather than fostering self-reliance and independence, nondisabled people's efforts at behaving positively imply an assumption that disabled people are needy and require help from nondisabled people (Makas, 1988). Thus, knowledge about the perspectives of people with disabilities is important to creating more effective alliances between disabled and nondisabled people.

A major opportunity and challenge for people with disabilities to gain greater societal access lies in the implementation of the Americans with Disabilities Act (ADA), passed by congress in

1990. The ADA represents a broad vision of access for disabled people. But the details of implementation are complex and subject to persistent efforts to compromise the regulations, such that access is less than assured. Definitions of what constitutes reasonable access is weighed against undue hardship on the part of businesses, institutions, and organizations--successful lobbying and litigation by representatives of these agencies can result in weak provisions for access.

The energy of a strong and organized disability community can be harnessed in efforts to press for stronger implementation of the ADA, and for social policies that respect the values of disability culture. Disabled activists and their allies are finding each other, organizing themselves politically, and further defining and affirming the meaning of disability for themselves in forums that include publications devoted to issues related to disability, such as *Disability Rag* and *Mainstream*; and through Internet listservs including MOBILITY, BLIND-L, DEAF-L, and others. In addition to the social support that these forums offer, disabled activists are using them to post action alerts related to pending legislation or other events affecting the disability community, in order to mobilize people with disabilities more effectively.

As people with disabilities find one another, work together for greater access, and share their stories, disability culture will be enriched and further developed. The current state of this distinctive and vibrant culture may only hint at its future potential. As disability culture becomes known to more disabled people, the sense of community and identity that it promotes may provide the source of a larger vision of societal access. This vision could pave the way for the emergence of future disabled leaders, who could work with other disabled people and their allies to create the fundamental, cultural transformations needed for a truly inclusive society.

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