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The Culture and Civil Rights of Disability:

Implications for Alcohol and Other Drug Prevention

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Introduction

Two world views in American society need to be reconciled. On one hand are people who believe that alcohol and other drug (AOD) problems are worthy of concern, amenable to improvement, and preventable. On the other hand, are People with Disabilities1 who face discrimination and stereotyping and who are affected by AOD problems at a high rate. There is a high level of denial in the Disability community about the damage to members and its community from AOD problems. Likewise, those concerned with AOD problems have virtually ignored the AOD problems of 43 million Americans with Disabilities. (Cherry 1988 & 1991; Heineman, et al. 1989; Moore & Polsgrove 1991)

These two world views have had little overlap, but can be reconciled. There is already a favorable environment for a powerful reconciliation to include People with Disabilities in AOD prevention and treatment efforts. A substantial beginning has been made to characterize AOD problems as a public health issue, which...???. (Cahalan, 1991) In addition, civil rights for People with Disabilities has been building since 1973. (Questions: How is this related to AOD problems in the previous sentence?] These are both recent phenomena.

An individually focused, medical model has been applied to alcohol problems in the years following Prohibition and for disability issues since the 1860s. This model attributes the problems solely to the individual. Societal or environmental factors have been secondary, if noted at all. Both AOD problems and disability issues are beginning to be addressed with a systems approach. There is the realization that no problem exists in a vacuum. The systems approach requires societal change for the amelioration of AOD problems and the problems created by the existence of a disability.

Definitions of Disability

There is no absolute definition of disability. The primary definitions are medical, employability, civil rights, and cultural. There is considerable overlap of the four. Medical diagnoses and employability are the eligibility definitions used for entitlement programs such as Supplemental Security Income and Social Security Disability Insurance. Three to five percent of the population has a disability using their [whose?] criteria. These [two definitions] reduce disability to a physical abnormality that mostly ignores the environment or culture in which the individual lives and works.

The civil rights definition is used in 504, 1973 Rehabilitation Act and is virtually identical to the [definition used in] the Americans with Disabilities Act (ADA) [of 1990]. According to the ADA the term "disability" means, with respect to an individual--

1. a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

2. a record of such an impairment; or

3. being regarded as having such an impairment.

The ADA definition applies to "43 million Americans." It is a useful definition when used to protect people's civil rights. The intent of the law is to insure that people are not unfairly disadvantaged solely because of a disability. It is broad and inclusive. Many who fall within the ADA definition of disability would be surprised to find themselves so included. [Why? Who?]

The final definition is cultural. It is the definition used by people with and without disabilities in their day-to-day lives to define disability status. It is a flexible definition based on experience and perspective rather than law. In this definition, Disability is a social definition shaped by religion, customs, media, and experience. It has a much to do with how someone looks [and feels?] rather than on a medical diagnosis. Two people with identical disabilities, both designated as having a disability by the ADA, might identify themselves differently, one as disabled and the other as non-disabled.

Viewing Disability as a cultural construct is to see Disability as an identification of unique individuals with a variety of differing conditions, diseases, disabilities, and handicaps who share a common experience. Generally, but not always, that common experience is [for the indivudal?] to be stereotyped and oppressed because of the Disability. Once [someone is] identified as having a Disability, it changes how that person is regarded and treated. Whether the Disability is visible or not also complicates the definition. As long as someone can keep a Disability invisible, the person is treated as non-disabled. This definition is critically important because it guides our day-to-day actions and interactions.

How can p[P?]eople with d[D?]isabilities as diverse as blindness, deafness, and paralysis see themselves as sharing an identity? People with Disabilities generally are not seen as being members of the larger [cultural?] group by the non-disabled. Sometimes the various groups will not recognize each others' membership. For instance, the Deaf [I thought we weren't supposed to refer to people with hearing-impairments this way. Deaf people??] recognize the cultural nature of their disability but have difficulty seeing the cultural origin of other disabilities. The situation is analogous to the identification of Native Americans or American Indians [politically correct]. Tribes with as different experiences as the Miwok of Northern California, the Mohawk in New York, and the Navajo all are identified as sharing a common label. [Is this good or bad?] Like People with Disabilities each group has its unique values and experiences, but there is a shared experience that bonds them all.

There is a growing movement of people who celebrate their Disability status and recognize their shared experiences [being part of a Minority group?]. In the Louis Harris Poll (Hill, et al. 1986 or1988?) taken in 1986 to investigate Disability issues just over 50% of the respondents who identified themselves as having a disability saw themselves as being like other minority groups. [Note: Not sure this proves the first point. Do they see themselves as part of a larger Disability group? Is 50% good or bad?]

Results of Discrimination

The 1986 Lou Harris poll found out far more about the experiences People with Disabilities [have as a group?] than their common identification as a minority group?]. Of those surveyed, 66% of the People with Disabilities were unemployed, 40% did not finish high school, and 50% live below the poverty line. Not only are the economic factors substantial but the poll revealed the social isolation that most People with Disabilities experience. Thirty-four percent of People with Disabilities go out to a restaurant once a week versus 58% of the norm; 66% had not gone to the movies the previous year versus 22% for the norm. The magnitude of these figures was so powerful that it gave a tremendous boost to the passage of the ADA. [How?]

Whether it is isolation or oppression or the same forces that cause the general populous to engage in high risk AOD use, People with Disabilities are adversely affected compared to the norm [in regard to alcohol and other drug use and abuse?]. Preliminary research has defined the general outlines of the problem. There is a consensus that (a) the rates of alcohol and other drug use and abuse varies among different disability groups and (b) abuse rates are generally much higher for People with Disabilities as a whole, than the national averages for the non-disabled. For instance, abuse rates of alcohol and other drugs for people with acquired brain injuries and spinal cord injuries is over 50 percent compared to less than 15 percent for the general populous. (Resource Center on Substance Abuse Prevention and Disability [RCSAPD] 1991)

The Disability Community

Given the fact that both the AOD and disability fields have been addressing the broader, less reductive [meaning?] issues in each of their respective areas of concern only within the last two decades, it is not surprising that the AOD problems in the Disability community have had limited investigation by either [field??]. (Cherry 1988 & 1991; Heineman et al, 1989; Moore & Polsgrove 1991). Beginning in 1990, a few State and federal resources were directed towards investigating the problems. The national efforts include: the OSAP funded VSA Educational Services Resource Center on Substance Abuse Prevention and Disability, the Leadership and Policy Development Symposium by the Institute on Alcohol, Drugs, and Disability, and the SARDI High Risk Youth project. The National Institute on Disability Research and Rehabilitation is funding a Research and Training Center on Substance Abuse and Disability. The states of Illinois, California, and Massachusetts have funded a variety of projects to improve access to AOD services by People with Disabilities.

Unfortunately, People with Disabilities have played a secondary role in guiding the definition of the problem and in designing the interventions. This is not surprising. The Americans with Disabilities Act in explaining the need for disability civil rights legislation notes that People with Disabilities have been "victimized by pity, paternalism, and charity." [U. S. Congress 1990] These attitudes have resulted in parents, doctors, special education teachers, rehabilitation counselors, and other professionals making decisions about the lives and welfare of People with Disabilities often without their consultation and never with their direction.

A Disability community with a set of definable, agreed upon needs, aspirations, values is a recent phenomena. As a part of the process many disenfranchised groups often reach a stage in redefining their identity where they begin to demand self-determination for their lives. This demand parallels and builds on American democratic traditions. (Omi & Winant 1986) People with Disabilities began to make demands for self-determination in the United States as early as the 1850s with the proposal to create Deaf communities "out West." (Padden & Humphries 1988) The contemporary efforts to gain self-determination and build a community began in the early 1970s. The demonstrations which resulted in the enactment of 504, 1973 Rehabilitation Act in 1977 mark the national emergence of the Disability Rights Movement or Independent Living Movement.

From the Declaration of Independence through the United Nations charter the basic desire to control ones own life is an acknowledged political right. (Ronen 1979) The post World War II period marked the rebirth and beginnings of many U.S, and international self-determination movements, including African Americans, women, Native Americans, Chicanos, and homosexuals. (D'Emilio 1983; Neuberger 1986; Scotch 1984) Probably the most familiar and influential are the efforts by African Americans to secure civil rights and economic security in the U.S. New tactics and revised self identity played a major role in the politics of the era.

The Disability Rights Movement is the result of the intersection of numerous, disparate social movements comparable to the efforts made by the gay and lesbian communities since the late 1940s. Many minority groups live or gather in physical proximity to each other and are raised in families where the minority group status is shared by everyone. This is not the case for most people with disabilities. They have formed a community as a conscious act as they recognized their devalued status.

A factor in the formation of the Disability community was the examination of the labels and identifiers for the members. In John D'Emilio's (1983) book about the changes in the gay and lesbian communities he noted that, "In evolving a shared language to articulate their experiences, gay men and women came a step closer to emerging as a self-conscious minority." This focus on a shared language is one of the hallmarks of forging a civil rights consciousness during the past thirty years. By redefining what they are called, minority groups define their identity as a group. The Disability community engages in seemingly endless debate both within the community and with the non-disabled public about the labels for individuals and the group.3

The Emergence of the [Disability?] Community

The post World War II baby boom created a group of people who have been likened to the "pig in the python." [What is this?] They are a demographic phenomena that by their sheer numbers have transformed American society in ways that were never anticipated. Included in this group of children were many who had disabilities. They were kept alive by the invention of antibiotics and an unprecedented knowledge and skill in health care developed during WWII and the Korean conflict. These children with disabilities shared in the dreams and aspirations of their generation. Their numbers were added to by traumatic injuries, particularly those caused by the increasingly omnipresent automobile. It was a time of unprecedented prosperity which helped give rise to an ethic of consumerism.

Concurrently, the Brown vs. Board of Education decision by the U.S. Supreme Court in 1954 and the Southern Civil Rights movement helped to develop a national consensus to accord civil rights to people who had been excluded from the mainstream. Groups other than African Americans were also organizing. By the mid 1960s Chicanos, Women, students, and others were becoming active. (Forbes, 1981, Scotch, 1984)

Children with disabilities were exposed to the self determination movements. Many of them had actively participated in some of them, particularly the anti-war movement and alternative life-style or hippie movement. They learned not only the mechanics of political organizing but the exhilaration and liberation of redefining their identity. As the baby boomers with disabilities who had attended public education began leaving high school and college they had a sense of entitlement to the goods and rights of citizenship enjoyed by their non-disabled peers. When it became evident that they were excluded they began the process of redefining their identity. They rejected the paternalism and pity that only garnered them token donations and began to build on the liberation movements of the 1960s.4

The consumer, civil rights, anti-war, and 1960s alternative lifestyle movements influenced the baby boomers with disabilities to become politically aware individuals. They learned how to organize people with shared concerns and values in order to develop a new vision of disability actualization. They created the political change necessary to establish a utopian vision for People with Disabilities.

Civil Rights [and Disability?]

Civil rights became a focus [of the disability community?] in 1977 as the newly inaugurated Carter administration hesitated to enact 504 of the 1973 Rehabilitation Act. For four years the Nixon administration had delayed enactment of the Act and People with Disabilities were anxious for the legislation to be enacted. The importance of 1973 Rehabilitation Act for People with Disabilities was the civil rights protections in 504. The section banned discrimination on the basis of disability in entities receiving federal funds. It was the first explicit Disability civil rights legislation. Although candidate Jimmy Carter had promised to implement 504 when he was elected, his appointee, Health, Education, and Welfare Director Joseph Califano, asked for more time to study the impact of the law.

The Disability community was not willing to wait any longer. Demonstrations were planned for federal offices across the United States. In San Francisco a sizable crowd of People with Disabilities picketed the Federal Building and then occupied the offices of HEW. They did not leave for three weeks. Califano signed the regulations that enacted the section. This was the public turning point of disability image and identity. No longer were People with Disabilities seen exclusively as passive, dependent, and pitiful.

The 1980s were a time to defend 504 and the Education of All Children Act, PL 94-142 which guaranteed that children with disabilities would have access to public primary and secondary education, from the deregulation efforts of the Carter and Reagan administrations. The Disability groups were successful and the legislation remained relatively intact. A consensus began to emerge among politically active People with Disabilities that broader legislation was needed to protect the civil rights of People with Disabilities. It was the beginning of the work, organizing, research, and lobbying that resulted in the Americans with Disabilities Act being signed into law on July 26, 1990.

[Recent Changes Affecting the Disabled Community]

The media images of disability changed significantly in the 1980s. Most notable were television commercials. For most of the decade no one with a visible disability was seen. Finally in a "life-style" ad from Levi's for their 501 jeans a young man in a sports wheelchair was shown wearing the jeans. Other ads followed. The ranged from a love story with two deaf people who cement their relationship with a Big Mac, to a mother in a wheelchair who finds the discounted item she has been searching for at Mervyn's. The inclusion of obvious images of disability helps to show that People with Disabilities should be included in our daily lives. They do not have to be institutionalized or kept in the back bedroom.5

The 1980s were also a time for an increase in the number of Independent Living Centers (ILC's). ILC's are community-based organizations that are governed by and provide services to People with Disabilities. They are based on the premise that People with Disabilities are the most knowledgeable experts about their own needs and issues and that programs serving disabled people should be designed to serve all disability groups. Currently there are ILC's in most major cities and many moderate sized communities in the U.S.

There was also an increase in programs [which ones?] at colleges and universities to provide access to post-secondary education. All of these events and system changess served to empower and train People with Disabilities and to provide models of Disability enfranchisement.

Federal Legislation, Disability, and Accessibility

The Americans with Disability Act (ADA) was signed into law in 1990, bringing the civil rights prospective of the 504, 1973 Rehabilitation Act to the private sector. It states, "Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society."

The protections of the ADA give People with Disabilities many of the same protections against discrimination that people of different ethnicity currently have. It is an opportunity to integrate People with Disabilities into the mainstream of American life.

Section 504, 1973 Rehabilitation Act has been in effect since 1977. The protections for People with Disabilities in that legislation require access to institutions receiving federal funding. Some sectors of society--post-secondary education is the most notable example--have committed significant staff time and funds to insure that People with Disabilities are treated equitably. Unfortunately, alcohol and other drug services have not been as responsive. They will have to become more responsive because one of the significant differences between 504 and the ADA is the right to private suit provided by the ADA.

Why now?

What makes 1992 a propitious time to examine and attempt to solve the AOD problems in the Disability community? For a start, there are a significant number of politically-aware and successful people with disabilities who have experienced and learned from their and other's problems with alcohol and other drug use. They are helping People with Disabilities and Independent Living Centers to be more aware of AOD problems. Because disability access is legally mandated by the Americans with Disabilities Act, awareness of the needs of the Disability community is growing among AOD treatment and prevention professionals.

It is important for People with Disabilities to be in positions of responsibility and authority for defining and solving the AOD problems in their community. Solutions determined outside the affected community are ineffective because they lack understanding of the complete environment. If the affected people continue to be excluded from decision making, the reasons for AOD problems to be so pernicious continue unabated. [Connection?] Truly effective prevention and recovery services for people with disabilities will occur only if members of the [Disability?] community band together, speak out, and advocate. A long term effective response is unlikely to occur without their efforts. (McCrone 1990).

The professionals who care about solving AOD problems in the Disability community can provide significant help. There is a commitment to community development and support in the prevention field. If the problems of the Disability community are viewed as similar to other disenfranchised groups like Women, Gays, African Americans, and Native Americans then respect and valuing the community's self determination can occur. Community development models are being used in other communities. They need to be used in the Disability community.

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Notes

1"People with Disabilities" is capitalized to be consistent with other minority groups, e.g. Native Americans, Gays, Women, when referring to the Disability community. When the reference is to the physical, rather than political or social, aspects the lower case is used. This distinction is used in the Deaf community. (Padden & Humphries, 1988)

2Arguing for societal responsibility and change does not relieve the individual of responsibility. Pointing to the shortcomings of society and working for the implementation of civil rights is effective on one level, but just as the alcoholic has been influenced by media, peers, and family the responsibility for sobriety rests with the individual. So too, do People with Disabilities need to take responsibility for their own actions. The reality of oppression is an explanation, not an excuse.

3The general consensus in the Disability Rights Movement and the Disability press is to use the phrase "P[p?]eople with disabilities." The use of "Americans with disabilities" in the title of the ADA reflects that general agreement.

4This attitude is still prevalent in many sectors of American life. An explicit example is the annual Labor Day Muscular Dystrophy Telethon.

5The new inclusion has meant that there is a now a beer commercial featuring a Person with a Disability. He is shown strenuously working out, finishing a race, and relaxing with his attractive, non-disabled, female coach. He promises her, as they drink a celebratory beer, that the two of them are going to sleep-in tomorrow, thus making their sexual relationship explicit. The voice over intones, "Budweiser, as genuine as you are." The ad clearly portrays and reinforces the multi-dimensional existence for which most of us, Disabled and non-disabled strive. In the process it ties the positive experience to beer drinking.[Is this good or bad? Not good from the AOD prevention standpoint]

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