

NOTHING ABOUT US WITHOUT US

Disability Oppression
and Empowerment

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the most material and spiritual ways. This struggle *incorporates their differences*, but, paradoxically, it also *differentiates them*. During the course of empowerment two things are going on: individuals are changing, and society is changing. Individuals necessarily, regardless of volition, begin a personal search for self-identity whenever they fight back, whenever they work to change their world.

It is on these dual levels that the accommodation (maybe not full resolution) of the contradictions between the individual and the collective, difference and unity, the personal and the political, is found. The internal struggle of a movement to achieve the broadest possible unity while supporting its activists' individual quest for self-identity must become motive forces in any liberatory effort or project. This contradiction between individual and collective goals must be accommodated or that movement will fail. This, unfortunately, has not been done with much success so far in other liberation movements. This contradiction is not irreconcilable. Whether we talk of struggle for a better life on a personal level or on a social level, these struggles are intrinsically political. This is one of the great lessons of the feminist movement: the personal is political, and the political must be personal.

This lesson can be extended to help resolve the contradiction between the individual and the collective, a relationship that is, at once, the basis of all liberation movements and one of their most difficult challenges. The question of how individuals long isolated by political, economic, and social marginalization can find one another and unite around their common experiences of oppression while accommodating one another's profound differences has an often perplexing history. The contradiction between the individual and the collective is particularly complex among people with disabilities because of our isolation, stigmatization, and fragmentation into categories (MS, MD, MR, MI, ED, EMH, LD, CP, SCI, deaf, late-deaf, hard-of-hearing, blind, visually-impaired, and so on).

There is a wide spectrum of experiences among people with disabilities that are filtered by class, gender, and race. Because disability oppression, like all human experience, is experienced between real people and not between people as individuals and structures as collectivities, social transformation requires that there must be a collective change in the way individuals think and behave.

The individual's relation to the collectivity is not a new subject. Jean-Paul Sartre's critique of Marxist orthodoxy in *Search for a Method* was published in 1968. Sartre sought to rescue Marxism from its one-sided fixation on the collective when he wrote, "It is precisely this expulsion

victory and defeat; the dominant culture tries, with alarming success, to "reach" us something different. We are taught to think in terms of isolated incidents and fragmented facts that stand still in time. The possibilities that a defeated strike can lead to greater political victories (for example, the outbreak of a successful revolution) or that a wheelchair, a symbol of dependency, can be the provider of great independence are ludicrous following the logic of the dominant culture.

Dialectics is predicated on something we know intuitively, that everything in life—politics, economics, art and culture, our individual beliefs and our very psyches—is constantly in flux. Dialectics is the best method for understanding oppression because its essence is change and oppression is a changing condition. The opposition to oppression is also a process, a process of recognition, identity, education, and resistance. If we were to take an optimistic but also realistic perspective, we might summarize the dialectic of disability oppression as follows: within the impossibility of the real end to disability oppression lies the possibility, even the probability, of significant political and social progress. It is in this context that I conclude by elaborating on (1) oppression in relationship to empowerment, the challenge to build a movement that unites as many people as possible; and (2) oppression in its relationship to liberation and freedom, the ultimate goals of such a movement.

Oppression and Empowerment

A fundamental paradox confronting the disability rights movement is that the progress of people with disabilities is contingent on significant economic development (the accumulation and expansion of capital) and, correspondingly, the emergence of (more) modern ideas about disability (the influence of capital) and, at the same time, the development of a movement that insists on social justice and equality (the restriction of capital) and an epistemological break with the dominant ideology (the rejection of capital).

Oppression is experienced both individually and collectively. No one person experiences a unique kind of oppression. This is because oppression is a social phenomenon and all social phenomena are either structured or influenced by political-economic and sociocultural factors. It is this dualism—individuality and collectivity—that is at the heart of personal and social transformation. People's struggle against oppression unites them in

of people, their exclusion from Marxist knowledge, which resulted in the renaissance of existentialist thought. . . . Marxism will degenerate into a non-human anthropology if it does not reintegrate people into itself as its foundation. . . . From the day that Marxist thought will have taken on the human dimension (that is, the existential project) as the foundation of anthropological knowledge, existentialism will no longer have any reason for being" (1968:179, 181).

Sartre's efforts were successful. The radicalism of the late sixties, not only in France but around the world, resonated with an interest in human and personal development, creativity, and responsibility. These movements did, albeit unevenly, maintain a coherent direction and have a great deal of success in forcing the dominant culture into structural and ideological changes. Sartre's insistence on the individual was not meant to undervalue the collectivity. He never pitted them against each other but always situated them in relation to each other. Undoubtedly, there is a phenomenology of oppression—a phenomenology that exists at both the individual and the collective levels.

In chapter 6, I suggested that the failure of most people with disabilities to identify with other people with disabilities is the principal contradiction that limits the DRM's potential influence and power. The relationship between the commonalities and differences in the disability experience goes to the heart of the identification question, raising fundamental issues for the DRM.

The notion of difference within disability is almost always missing in the major research on disability. This is the case in Erving Goffman's influential book *Stigma*. Goffman not only depoliticized the oppression of people with disabilities, he treated disability as uniform. Goffman's deviance theory failed to comprehend the divergent forms and experiences of oppression because it did not recognize differences among people with disabilities. One only has to ask simple questions to raise serious doubts about its explanatory power. For example, what about those with hidden disabilities (is cancer "stigmatized" only if people gossip?), or the "stigma" status of a destitute, black, gay man with AIDS? Does deviance theory help us to understand why a nonverbal Mexican immigrant with cerebral palsy dies mysteriously in a Chicago hospital after an alleged experimental treatment? Why do Maoris with renal failure find no access to dialysis? What about the class, race, or gender differences within disability? Does anyone imagine that a black sixteen-year-old boy with a spinal cord injury received from a gunshot, who lives

in a housing project in Brooklyn, experiences the same stigma or stereo-type "problems" of a sixteen-year-old spinal cord-injured white girl who was hurt in a diving accident and lives on Martha's Vineyard?

As Adrienne Asch and Michelle Fine noted in their introduction to *Women with Disabilities*, "To date almost all research on disabled men and women seems simply to assume the irrelevance of gender, race, ethnicity, sexual orientation, or social status. Having a disability presumably eclipses these dimensions of social experience. Even sensitive students of disability (for example, . . . Goffman 1963) have focused on disability as a unitary concept and have taken it to be not merely the 'master' status but apparently the exclusive status for disabled people" (1988:3).

The problems with theories that disregard differences within social groups are primarily twofold. First, such theories situate oppression in the knowing subject: one can be oppressed only if one knows one is oppressed. This implies that membership in an oppressed group is limited only to those who identify with that group. You cannot experience the stigma of disability unless you think of yourself as having a disability. You do not experience stigmatization unless you "feel" it. For the DRM, this distinguishing criterion is important. Second, if this kind of identity theory is correct, oppressed groups are reduced to clusters of interested individuals who can only be interested in their own needs. The DRM in this sense becomes an "interest group," like unions, pro choice groups, tobacco growers, and thousands of other groups interested in a particular policy, budget, or law. We are not oppressed; we have neglected needs. Again, these efforts emasculate the essence of disability oppression. They place disability in the "needy" category (those who need) as compared to a "have" category (those who have). People are not oppressed. They are stigmatized by an uneducated public and therein have unmet needs.

Recently we have witnessed the opposite error. Instead of framing the question of oppression only in terms of the collectivity of a particular group, which obliterated the profound differences within that group, all sorts of books and articles have appeared which frame the question of oppression only in terms of the individual. This postmodern or poststructuralist position revels in diversity. By seeing difference everywhere, its adherents must reject unifying commonalities anywhere, except at the most discrete levels. In the end, society is just too complex, human experience too singular to allow any (meta)theory of disability oppression.¹ When universality is abandoned, when difference becomes everything at the

expense of collectivity, only the lonely, isolated individual remains. This perspective, like the one it is so determined to repudiate, continues to pit the individual against the collective and refuses to appreciate the dialectical relationship between them.²

In his article on postmodernism and Marxism, Manning Marable, a leading African-American social critic, charts a third course, "transformation." Marable distinguishes two historical tendencies within the African-American community: inclusion (associated with civil rights advocates Frederick Douglas, Martin Luther King, Jr., and Roy Wilkins); and black nationalism (associated with Marcus Garvey, the young Malcolm X, and Huey P. Newton). Marable's alternative paradigm, transformation, is associated with W. E. B. DuBois, Paul Robeson, Fannie Lou Hamer, and the older Malcolm X. Marable writes that transformationists

have sought to deconstruct or destroy the ideological foundations, social categories, and institutional power of race. Transformationists have sought neither incorporation or assimilation into the white mainstream, nor the static isolation of racial separation, but the restructuring of power relations and authority between groups and classes in such a manner as to make race potentially irrelevant as a social force. . . . This critical approach to social change begins with a radical understanding of culture. . . . Culture is both the result and consequence of struggle; it is dynamic and ever changing, yet structured around collective memories and tradition. . . . To transform race in U.S. life demands a dialectical approach toward culture which must simultaneously preserve and destroy. We must create the conditions for a vital and creative black cultural identity in the arts and literature, and in music and film. . . . But we must also destroy and uproot the language and logic of inferiority and racial inequality. (1995:86)

This third paradigm has much to offer people with disabilities and the disability rights movement. It locates ideology (of inferiority, false consciousness, and the failure of identity) on a systemic level—in oppression. It also argues for the possibility of an organized resistance to people's common oppression—empowerment. Transformation offers the real possibility of resolving the contradictions between the individual and the collective constructively. Only by simultaneously constructing our own identity as people with disabilities and destroying the categories that separate and differentiate us as a group can we transform our own collective realities as poor, powerless, and degraded individuals.

Oppression and Freedom

What is the strategic goal of the disability rights movement? Is it strictly human rights, or is it liberation and freedom? What exactly would liberation be like for people with disabilities? What is the best way to go about ending disability oppression, and on what basis do we struggle for social change? Is the demand *Nothing About Us Without Us* a genuine, liberatory call for self-determination or a plea for recognition by the dominant culture? What are the barriers to liberation and freedom, and what are the challenges for the disability rights movement? Do the necessities of everyday life provide the resources and practical experience to fashion a more liberatory existence, or do they act as fetters to progress? There are many questions with many answers.

Freedom seems to be the only true negation of oppression. It is a condition free of oppression. For some, freedom is an absolute condition. For others, freedom is not an absolute state or a state of mind. It is predicated on an evolving recognition by people of what they need and how to satisfy those needs. As Friedrich Engels wrote in *Anti-Dühring*, "Freedom is the recognition of necessity" (1878[1972:167]).³ This is a real-world proposition not separated from a state of mind but bound up with it. Liberation and freedom must be understood as processes, for they transform the individual and collectives' material and spiritual necessity.

Need is not a desire or a want. It is a socially ordered (configured) condition. For example, personal hygiene is a universally valued need. This need can be easily met for those with modern bathrooms. But consider the hundreds of millions of people who do not have modern bathrooms. In many cases, simple necessity is not so simple.

A more vital need is drinking water. Every tourist who visits the Third World is told not to drink the water. In Mexico, the result of failure to comply is called "Montezuma's revenge." In fact, you cannot drink the water because of the social priorities of the elites. It is not because Third World countries do not have sanitary engineers. It is because it is too costly for the elites, and besides they can make a lot of money on bottled water. You can bet the water that comes out of their taps is as good as any in the United States or Europe. The point is that the social conditions of, in this case, underdevelopment prevent tap water from being purchased. Of course, poor people drink the water, so it is not surprising that the diseases associated with drinking contaminated water (hepatitis A, cholera, parasitic infections) are prevalent throughout the Third World.