

Disability culture

WRITTEN BY

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Disability culture, the sum total of behaviours, beliefs, ways of living, and material artifacts that are unique to persons affected by disability. Particular definitions of culture take many different forms and are context-bound (dependent on the cultural and geographic context in which they are formed), but three common ways of thinking about disability culture are (1) historical, (2) social and political, and (3) personal and aesthetic. Historical definitions of disability culture focus on art, poetry, language, and social community developed by disabled people. Definitions of disability culture that blend the social and the political focus on a minority-group distinction with common values of social and economic justice, radical democracy, and self-empowerment. Notions of disability culture grounded in the personal and the aesthetic emphasize a way of living and positive identification with being disabled.

Although concepts of culture vary as much as concepts of disability, one concept does seem clear. The experience of disability is embedded in culture and the social relations of culture. Those relations influence the ways in which the importance and meaning of disability are defined, and they shape the association of disability with functional impairment. Functional impairment generally is recognized as a loss or limitation of physical, mental, or sensory function, typically on a long-term or permanent basis. Functional impairment gives rise to disability, which, because of physical and social barriers in the environment, limits affected individuals' opportunities to participate in the life of a community to the same degree as nondisabled individuals. It should not be assumed, however, that the severity of an impairment equates with severe functional limitation or

disablement. Rather, the meaning and significance of an impairment derive from the treatment of the individual in the broader cultural context within which that individual lives.

Two dominant models of disability have been developed in the popular and scholarly literature on disability in relation to the distinction between impairment and disability. The social model of disability focuses on environment and assumes that impairment is not as significant as the disability that is constructed by social attitudes and cultural mores that underlie the structural environment. In the social-model way of thinking, the environment disables the individual and needs fixing. The second model of disability is known as the medical model. That model assumes that the individual needs fixing in order to adapt to the environment—either by therapy, medicine, surgery, or special treatment. A third model, sometimes called the traditional model of disability, comes mainly from less-developed countries and is not as well known as the social and medical models. It asserts that disablement is created specifically by traditional religion and culture. In the traditional model, people with impairments may be regarded as unfortunate, different, or blemished in some way, and, as a consequence, they are sometimes perceived as having inhuman or nonhuman traits because they are considered unable to perform traditional social roles. Each of the three models relates directly to culture and provides a starting point for understanding how disability culture is developed or enacted.

Disability Culture: The Beginnings

Although disability culture began in different ways in different countries and regions of the world, the primary impetus for its development, particularly in the modern era, has been attributed to the institutionalization and segregation of the disabled from mainstream society. In the United Kingdom and other parts of western Europe, for example, organized groups of disabled people raised the consciousness of their members and brought them together to form a social movement for change during the latter part of the 20th century. The social movement emphasized inequalities in society and

focused on economic and institutional discrimination. In the United States, organizations of disabled people built on the momentum of the American civil rights movement, focusing on litigation and legislation connected to civil rights. In that country the disability rights movement began to take form in the 1960s, developing largely as a political movement that emphasized identity as citizens and individual rights.

The 1970s saw remarkable growth in disabled communities, an expansion that ultimately spawned what became known as disability culture. In Africa during that decade, young disabled people in Zimbabwe were institutionalized in residential missionary schools. Isolated from their families and geographically removed from society at large, young people with impairments formed strong ties with each other and a support system among themselves. At one school, in Nguboyenia, self-described “inmates” decided to start a social club, through which they organized excursions and held discussions that enabled them to become aware of their solidarity and the common injustices they experienced. They launched a countrywide campaign and membership drive. Eventually they established clubs in every district of Zimbabwe and a headquarters in the city of Bulawayo that they called Freedom House, where they could congregate as a community and develop a shared group identity. The organization later became known as the National Council of Disabled Persons of Zimbabwe.

In other less-developed countries, such as several other African countries and India, disabled people’s organizations were influenced by fundamental human needs (e.g., shelter and food). The need to eradicate extreme poverty in those countries led to the organization of efforts that coupled disability with development, thereby demonstrating the ability of disabled persons to contribute to social and economic advancement. In Latin America and Asia, organizations of disabled people tended to focus on liberation from basic forms of institutionalized oppression as well as on individual human rights and basic needs. Their agendas tended to be broad and all-encompassing.

From those beginnings of political and social organization to confront injustices in mainstream society and to advocate for basic needs and rights, notions of a disability culture began to be talked about and embraced. Impaired individuals who had been “conscientized” to think of their impairments as disabilities constructed by societal practices and norms began to develop a disability pride. Through their collective political association and social interaction with other “disabled” people, they began to realize their individual strengths and abilities and seek ways to celebrate them. Their initial focus on external oppression that manifested itself in segregation, social injustice, and discrimination led to a realization of the ways in which they had internalized that oppression. Negative societal attitudes, discrimination in institutional practices, and cultural beliefs that dehumanized the disabled began to be challenged at a personal level.

Supported by their disability communities (political and social) and exposed through those communities to a different way of thinking about themselves in relation to society at large, disabled persons increasingly became interested in sharing their unique thoughts, actions, and beliefs. That interest manifested itself cross-culturally in unique expressions of literature, poetry, dance, film, theatre, and music.

Expressions Of Disability Culture

Numerous individuals who identify as disabled express disability culture as artists, poets, and actors in theatre groups and can be found in all regions of the world. Many such individuals are supported by institutions such as creative art centres and national disability institutes.

Disability culture is also expressed in the academic field of [disability studies](#). Disability-studies scholars worldwide are supported by their own networks of academic communities, such as the Society for Disability Studies, the Centre for Disability Studies, and the Association of University Centers on Disabilities. Since the latter part of the 20th century, disability-studies scholars have challenged

perceived knowledge in such wide-ranging fields as anthropology, sociology, feminist epistemologies (study of the origin and limits of knowledge concerning gender), history, arts and humanities, and education as well as the medical fields of [public health](#), bioethics, genetics and genome research, and rehabilitation.

Cultural representations of disability in disability studies have taken many forms within those fields. Examples include the exploration of changing images of disability across time and the analysis of negative images of disability in mainstream literature, art, and film; scholars have uncovered and exposed images that are inadequate, distorted, or contrived. Such critiques have focused on culture as discursive practice (the codified visible representations of culture) and in the process have encouraged transgressive responses among the members of disability culture.

Ethnographies, autobiographies, and narrative stories from authors worldwide provide detailed descriptions of the lived experience of disability. They offer in-depth cultural images of personhood that capture the wide variety of individual experiences of disability. Examples of such works include American anthropologist Vincent Crapanzano's *Tuhami: Portrait of a Moroccan* (1980), American writer Mariana L. Ruybalid's *A Pattern of Silent Tears* (2003), Indian disability rights activist Malini Chib's *One Little Finger* (2011), American sociologist Irving Kenneth Zola's *Missing Pieces: A Chronicle of Living with a Disability* (1982), and American anthropologist Robert F. Murphy's *The Body Silent: The Different World of the Disabled* (1987). At the same time, popular media such as newspapers and magazines preserve and record the history of disability and disseminate cultural knowledge of disability.

In the 21st century, expressions of disability culture became increasingly focused on the celebration of difference. Various visual and textual manifestations of a fast-growing disability culture encouraged the development of shared values, such as an acceptance of difference, a tolerance for ambiguity, and a flair for dark humour.

Differences In Disability Culture

Disability movements conceive of disability culture as primarily social and political in nature, whereas academic communities view disability culture from predominantly historical, discursive, and linguistic perspectives. In other cases, individuals view disability culture in personal and aesthetic contexts, constructing a culture through encounters that shape individual identity and identity formation. Individual interpretations of their personal experiences allow for multiple expressions of cultural identity. Aesthetic pride in the impaired body, for example, represents one aspect of personhood related to disability culture.

However, for some individuals with impairments, personal experiences unrelated to disability take precedence in defining their identity. Experiences of racism, for example, may be more immediate and significant than being disabled. For others, being blind is more important than being “disabled.” Still others with no visible markers of impairment or disability may feel marginalized by those with visible traits. To complicate the issue further, some individuals and disability organizations reject the notion of disability as the primary marker of personhood.

Furthermore, within different cultures, constructions of disability may portray disabled persons as heroic, autonomous, and capable or as invalid and entirely dependent on others. In some cultures, religion may play a central role in the formation of a disability culture. A disabled child, for example, may be seen as a gift from God or as divine punishment. In other cultures the genetic transmission of disabilities in blood-related families may be seen as an expression of honouring strong family foundations. Ultimately, each of those different cultural practices and beliefs influences a person’s disability identity and his or her identification with a disability culture.

But the three ways of thinking about disability culture described above—historical, social and political, and personal and aesthetic—should be understood to take expression simultaneously. Thus, the

boundaries between personal disability identity pride and notions of disability community often are blurred. Identities forged from personal experiences may be supported and further developed by identity with a particular disability community—whether social, political, or academic. Disability culture as social and political coexists with personal values of disability pride. All of those forms of disability culture are expressed through textual, discursive, linguistic, and artistic forms.

Disability Culture In The 21st Century

Understanding disability culture offers several possibilities for future thinking, study, and practice. Those possibilities include (1) study of changes in the way disability and difference are defined and understood, (2) changes in thinking about disability identity in relation to society as a whole as well as in relation to disability movements, and (3) changes in the ways that people think about and develop supportive communities.

Defining disability and difference

Disability, disablement, and impairment are universal. They know no national, societal, or cultural boundaries. Anyone can become disabled—regardless of age, class, race, or gender—through birth, accident, illness, war, poverty, or advanced age. Most individuals, at some point in their lives, will experience disability, disablement, or impairment. The vast majority of disabled people worldwide live in less-developed countries. Most of those individuals live in rural areas and experience their cultural identity in traditional agrarian societies. It has been estimated that in some regions of the world as much as 25 percent of the population is impaired. In some countries disability is a condition of everyday life, such that disability and impairment are not merely the experience of a [minority group](#) but rather the normal condition of humanity. From that perspective, distinctions between disabled and nondisabled individuals that have formed the basis for developing disability culture become problematic. When all

individuals are included, whether because they are frail, limited, or mortal, there is no distinct identity.

Studies of disability culture indicate that people who have impairments often define themselves not by their impairments but in relation to disablement in cultural contexts. Different cultural beliefs and practices, however, make biological impairment difficult to define or to separate from disablement. Notions of the impaired body shift and change, depending on the cultural context and historical times. Definitions of disability culture and the process of enacting that culture suggest that embodiment, or the experience of disability, may be a more-effective way of understanding impairment than attempting to refine or develop universal descriptions and categories of impairment. Seeing disability and impairment as embodiment recognizes historical and cultural aspects of impairment that are inseparable from the biological aspects.

Recognizing multiple identities

Disability culture has been associated with identity politics (political views and activities based on shared injustices) because of its emphasis on collective identity to work for [social change](#). That collective identity is based on an understanding of shared oppression and has the principal goals of forging positive images and changing society to meet the requirements of social justice and [equity](#). Notions of disability culture that emphasize a collective identity have been criticized by disability activists and disability scholars as the [paradox](#) of disability culture. The paradox lies in the argument that claiming unity against oppression is actually a source of oppression in itself. In other words, claiming unity leads to simple [dichotomies](#) of “us” (disabled) and “them” (nondisabled), ignoring and devaluing differences among disabled people.

However, all people have multiple identities, which take on different meanings and importance in different contexts. As an example, for some disabled people in the United States, being a woman, being gay

or lesbian, or being [African American](#) can be more disabling in relation to societal discrimination than having an impairment.

One of the core values of disability culture is acceptance of difference. At the same time, the social model of disability aims to fix the environment so that differences no longer make a difference. The paradoxes of unity and difference inherent in those values and goals continue to be addressed at a practical level and in theory.

Less-developed communities

Although rates of disability are on the rise globally, important differences exist between developed and less-developed countries. In many developed countries, the general rule of thumb for counting the prevalence of disability is 10 percent of the population. In less-developed countries that number tends to be greater, largely because of conditions of poverty. Overall, disabled individuals represent one of the largest minority groups in the world.

The rise of disability culture depended primarily on community building, either as a result of physical exclusion from society (via institutionalization) or as a result of resistance to social, political, or economic exclusion from basic human rights, employment opportunities, or social roles and responsibilities connected to personhood. The social and political movements that developed from community building have been composed largely of middle-class individuals from industrialized countries. Those movements created social and political agendas within a disability culture that is based on Western assumptions about disability. The growing movement in less-developed countries exposes the limitations and narrow vision of earlier Western movements and emphasizes the need for a broad cross-cultural and comparative vision of disability culture. Such a vision necessarily takes into account notions of personhood and “the body functional,” as well as traditional models of disability and the broad vision of disability and development.

Globalization of disability culture brought with it technological and medical advances that have greatly benefited disabled people. Examples include electronic vision and hearing devices, physical mobility devices, and opportunities for communication via the Internet. At the same time, those technologies are not available to many disabled persons living in less-developed countries, because of poverty or a lack of health or technological infrastructure. For that reason, globalization carries opportunities as well as dangers. For example, although globalization provides greater numbers of disabled people with access to disability culture, those numbers are likely to represent mainly the privileged classes, thereby increasing the divide and exclusiveness in disability communities.